

A COMPREHENSIVE AND SENSITIVE APPROACH TO RAPID AUTOPSY
EDUCATION VIA A WEB-BASED INTERACTIVE

By
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Abstract

Johns Hopkins University is currently performing rapid autopsy procedures as a part of the Legacy Gift program to advance cancer research in the areas of prevention, diagnosis and treatment. Procuring research samples post mortem allows for examination of the cancer at its terminal stage and for the collection of larger amounts of tissues than can typically be donated during life. Performing the procedure within twelve hours of death allows for the collection of living cells and undamaged DNA and RNA.

There are multiple barriers to both autopsy and rapid autopsy identified by physicians, patients, and families primarily stemming from a lack of education about the procedure and its benefits and from uncertainty of how to approach the conversation. A search of online resources yielded little information about autopsy and rapid autopsy and even less specifically directed to patients and families. The goal of this project was to create a prototype for a series of interactive educational modules that would present information about autopsy and rapid autopsy in narrated animations and in text format to be displayed on the Legacy Gift website targeting both a medical and lay audience.

Seven areas of education were identified. Each subject was broken down into a total of 42 sub-sections and a script for each was drafted. The subject of the rapid autopsy procedure was selected for the prototype. One animation for the sub-section of why rapid autopsies are performed was created and, in conjunction with script, was used to populate a portion of the module. The module contains nine buttons, one for each of the eight sub-sections for that subject and one button to display all text.

Six health care providers and rapid autopsy program team members evaluated the animation for its appropriateness for the patient audience and there was a consensus that the animation can help patient understanding. The major challenges during the creation of this resource were addressing it to a broad audience and the sensitivity of the subject matter. Completion of the module and further user evaluation would benefit the continued development of this new educational resource.

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Introduction

Current Cancer Research Direction and Limitations

Cancer is a genetic disease that arises from gene mutations which alter how the cell functions. Even after a cancer develops, it will continue to evolve new mutations. This process of development can lead to genomic heterogeneity even within the same tumor (Gerlinger et al. 2012, Spunt et al. 2012). With this understanding, the field has turned toward deciphering tumor biology to advance cancer prevention, diagnosis and treatment.

Researchers are looking for answers for how mutations are occurring and why. They are looking for new biomarkers for earlier diagnostics, determining prognosis, treatment assignment and treatment response monitoring. Specific to treatment, there is a push to develop personalized medicine with targeted therapies and immunotherapies developed from the patient's own cells (Wu et al. 2008, Wu et al. 2015). This type of research is limited by access to tissues. Samples from biopsies tend to be very small in size and are limited to which tumors and regions of a single tumor can be sampled without subjecting the patient to undue risk. This poses a disadvantage when tumors are heterogeneous. Additionally, samples taken for diagnosis that do yield enough tissue for research, may not be preserved in a manner ideal for research (Spunt et al. 2012). Surgical tumor resections can provide a larger sample. However, these samples are from earlier cancer stages when known therapies may still be effective and the cancers have not yet evolved to their terminal state (Alabran et al. 2013). On rare occasion, samples may be obtained strictly for research purposes but with limited access to tumor sites. Generally, testing is reduced during end stage cancer when little else can be done. This results in limited access to tumors after they have become therapy resistant, restricting knowledge of the final progression of a cancer at death.

What is a Rapid Autopsy

Rapid autopsies are currently being performed at Johns Hopkins University for cancer research including prostate, ovarian, pancreatic, breast, melanoma, sarcomas, renal, and pediatric brain cancers with plans to expand to other types. The rapid procedure is performed to provide preserved DNA and RNA samples and normal and abnormal live tissue donations to researchers. It also allows pathologists to examine the full extent of the disease, and to compare autopsy findings to findings based on imaging and biopsy.

The term “rapid” is used because the rapid autopsy procedure takes place relatively shortly after death in comparison to the standard autopsy procedure. Regular autopsies are typically performed 12-24 hours after death and take approximately 3 hours to complete. Rapid autopsies are performed preferably within 6, but up to 12 hours after death and will take 4-8 hours to complete. Performing the procedure shortly after death is imperative for obtaining live and non-degraded samples (Broniscer et al. 2010). A complete rapid autopsy includes the following steps. The procedure begins with an external exam as is done for a traditional autopsy. Unlike a traditional autopsy, sterile procedure is used for the incision. This involves sterilization of the skin and use of sterile scalpels, gloves, and sample containers. The first incision is a standard Y or U-shaped incision to access the thoracic, abdominal and pelvic organs and major vessels. The anatomy is examined in situ. Research samples may be taken at this time. Then the organs are removed “en block” unless the specific case would benefit from removing the organs separately. The organs and major vessels are then sectioned and examined and additional research samples may be taken. A second incision is made over the crown of the head to access the brain and the prior steps are repeated. The eyes are also removed but no incision is required. If the particular cancer involves other areas of the body, the procedure may again deviate from the standard autopsy procedure and require additional

incisions to obtain samples. This will only be done with prior consent. Samples are kept fresh, frozen, and fixed in formalin. After the procedure is complete, the body is released to the funeral home. The organs are kept until the autopsy report is finalized and are then incinerated. Modifications can be made to the procedure at the family's request.

Benefits of Rapid Autopsy

Benefits to Researchers

A complete autopsy allows access to large amounts of both normal and abnormal tissues, multi-regional samples within the same tumor, all tumors, live tissue, and late-stage treatment resistant tumors (Broniscer et al. 2010, Spunt et al. 2012). Researchers can also obtain samples of non-degraded DNA and RNA (Broniscer et al. 2010, Spunt et al. 2012). Access to these types of samples benefits cancer research in the following ways:

- Abundant samples of both normal and abnormal tissue create the opportunity to bank large amounts of tissue for future research. It also make samples available to multiple researchers throughout the country and internationally. This is especially important for rare cancers with few cases available for study. Having both types of tissues allows researchers to compare the tissues of the same patient to identify mutations.
- Multi-regional samples, meaning multiple samples from each tumor, allow researchers to look for genetic mutation variances that occur both within single sites and between multiple sites of spread. This may include genetic variances within the same tumor and genetic changes that occur as the cancer metastasizes.

These findings can be used to identify new targeted gene therapies

and new biomarkers (Spunt et al. 2012). The findings can be compared to other cancer cases to look for new treatment options that may be effective for multiple cancers. They can help identify if existing treatment options may be efficacious for other cancers and why some treatments were not effective (Spunt et al. 2012).

- Living tissue provides the opportunity to grow cell cultures with proliferating cell lines and clonal populations. Cells with the greatest propensity for proliferation will take over, creating a genetically uniform cell culture. This is ideal for repeating experiments. It provides a simple cell model that can be used for initial drug tests.

Living tissues can also be used to create xenografts, where human tumor tissue is implanted in an animal to create a model for study. This allows growth of tumor over generations of a species that are genetically and environmentally similar to the tumor in the patient. Xenografts are a better predictor of how well therapies may work in the patient than cell lines and can also be used for genetic sequencing.

- Tissue and blood samples provide tumor RNA. The sequencing of RNA is important for looking at mutations that occur during transcription directly from DNA and identifying errors in alternative splicing. Researchers can also examine how much of the gene is coded and whether it is too much, too little, or a healthy amount of each product.
- Immunohistochemistry studies use antibodies on fixed tissue slides to identify proteins indicative of cancer. This can be used for determining diagnosis and prognosis. These types of studies provide the

opportunity to look for additional biomarkers.

- Proteomic studies evaluate at the gene product. This is important because proteins can undergo additional modifications after translation that can alter their shape and function. Researchers can compare the normal for each protein to identify the abnormal, which can indicate a disease or condition. The presence or absence of abnormal proteins can help determine diagnosis and if treatment is working.

Benefits to Healthcare

Diagnosis and monitoring is subject to the limits of medical technology. A complete autopsy allows the pathologist to determine how the cancer has spread, how it caused death, the effects of the treatments, and confirm or disprove clinical diagnosis and findings (Spunt et al. 2012). Autopsies can help identify conditions commonly misdiagnosed or undiagnosed, which can improve diagnosis, treatment, and survival (Spunt et al. 2012). They serve as an important tool for monitoring and improving the quality of healthcare.

Benefits to the Patient and Family

In addition to the direct benefits to research the patient and family may also find some solace by participating. Perceived benefits may come with the knowledge that they are helping others, that they are continuing the fight against cancer, that the contribution may lead to the understanding how the cancer caused death, that they may learn more about the full extent of the disease, and that the autopsy may confirm they did everything they could for the patient (McIntyre et al. 2013). In some cases, it may also contribute to the cosmetic result for a viewing. Understanding the cause of death and a desire to help others and medical research are commonly stated reasons families choose to consent to

an autopsy (Spunt et al. 2012).

Autopsy Barriers

Regular autopsy rates in hospital deaths have dropped from approximately 50% in the 1950's to approximately 5% of cases today at most centers (Hooper and Geller 2007). This is despite a majority belief among physicians that modern technologies do not preclude usefulness of the autopsy and a belief that autopsy results could affect how they practice (Hooper and Geller 2007). Common barriers to autopsy cited by family are lack of information and education of benefits, psychological stress, religious reasons, and logistics. Autopsies are also hindered by physicians' lack of awareness of benefits and reluctance to ask patients and their families (Alabran et al. 2013, Spunt et al. 2012).

Research has also been done on barriers specific to rapid autopsies. Families cite a lack of educational information including being made aware of the option, and logistics as major barriers (Alabran et al. 2013, McIntyre et al. 2013). Medical staff cite logistics, lack of awareness of programs and/or their value, reluctance to ask and uncertainty or how and when to ask, and no immediate reward for physician are factors that interfere (Alabran et al. 2013, McIntyre et al. 2013). Frequently asked questions regarding rapid autopsy at Johns Hopkins University address concerns that the procedure will affect a viewing, concerns that the family will incur the cost, and question how soon after death the procedure must take place (Johns Hopkins University n.d.). Despite the barriers and concerns of families, patients and providers, multiple studies have shown that patients are highly interested in participating in rapid autopsy tissue donation. (Achkar et al. 2016, Alabran et al. 2013)

Current Education Offered to Patients

At Johns Hopkins University, patients and families are typically informed about

the rapid autopsy program by their oncologist or surgeon. They may also then be directed to the Johns Hopkins Department of Pathology Rapid Autopsy website where information about faculty, staff, researchers, publications, external links, frequently asked questions, and a memorial site are available in text format (Johns Hopkins University n.d.). No other take home resources are currently available.

There are other similar research autopsy programs across the country. A review of online information available for some of these comparable programs showed common practice is to present the information in text format and occasionally include a picture. The information made available was not always directed toward patients and did not always address the specifics of participation or frequently asked questions. The information was often presented all at once, primarily in paragraph format with lengthy sentences and paragraphs indicative of a higher reading level.

General Healthcare Communication Complaints

Common general healthcare complaints of patients and their relatives include “not receiving information or being given the option to participate”, “not being met in a professional manner”, and “insufficient respect or empathy” (Jangland, Gunningberg, and Carlsson 2008). An overall complaint, specifically regarding healthcare information on-line, is that the information is presented at too high a reading level and includes incomprehensible technical jargon (van Weert et al. 2011). This may be particularly problematic for those who have low health literacy.

Health Literacy

A review of health literacy in America in 2006 reported that only 12 percent of adults were found to be “proficient”, 53 percent were “intermediate”, 22 percent were “basic”, and 14 percent were “below basic” (Kutner et al. 2006). Even for those found to

be proficient, the additional stress of symptoms and diagnosis may impair comprehension (Houts et al. 2006). Information about autopsy and rapid autopsy currently available online tends to be in text format, which appeals to few learning theories. Images and video are also available but are limited and tend to be too graphic for patient education. This would include visuals of actual organs. However, having something available at home with appropriately sensitive visuals and narration can aid comprehension and satisfaction (van Weert et al. 2011, Houts et al. 2006). This is may be particularly helpful because those who do have low literacy may not admit this to others including their healthcare providers (Parikh et al. 1996).

Audience

The primary target audience includes two groups. First are terminal cancer patients and their families from Johns Hopkins University who are directed to the rapid autopsy website by their oncologist to learn more about the rapid autopsy program. Patients and families may be approached at different stages of disease depending on when the provider feels it is most appropriate, although the conversation will typically take place during discussion about hospice. This conversation will usually be occur during after the disease has progressed to a later stage but while the patients are still functional and usually still attending appointments. The patients and families are from diverse cultural backgrounds and education levels and may be from either the adult or pediatric population. The second group includes physicians and health care providers who are not familiar with the autopsy and rapid autopsy procedures and benefits. This group may be presented this material during national Pathology and cancer meetings. The secondary audience consists of patients, families and healthcare providers who may come across the site searching for similar programs.

Project Objectives and Scope

Autopsy is a difficult subject to approach and discuss for families, patients, and health care providers (McIntyre et al. 2013). The primary goal of the project is to create an appropriately sensitive and educational resource about autopsy and rapid autopsy for patients, their families, and health care providers. Seven topics are addressed including cancer development, autopsy, rapid autopsy, the participation process, the benefits of rapid autopsy, research types that can be performed with rapid autopsy donations, and research outcomes.

This resource comes in the form of a series of interactive modules that can be made available on the existing Johns Hopkins University Pathology Legacy Gift website or presented at meetings. Use of interactive media was selected because it allows the information to be presented in text format and in an animated format with narration. Supplying the information in multiple formats is ideal because it complies with multiple learning theories. This format also gives the user control over how much information he or she views and what information is viewed. Having the information available online makes it easily accessible, easy to revisit, and available in the privacy and comfort of one's own home and will serve to demystify the autopsy process and address preconceptions. Short animations are also an engaging resource that can be easily embedded directly in presentations. Additionally, as independent clips, only the most relevant animations can be selected for inclusion so each presentation remains concise and tailored to the specific audience.

This thesis covers the creation of the complete scripted information. It covers the creation of a working prototype of the interactive module, the development of all of the storyboards for the rapid autopsy section and the development of the first animation of that section. Evaluation of the animation was then completed by stakeholders. Feedback at this stage would inform the development of the remaining components.

Materials and Methods

Content Preparation

Definition of Content

This project was conceived by Dr. Jody E. Hooper. The goal was to create an educational resource with visual components about autopsy and rapid autopsy performed at Johns Hopkins for a broad audience. This resource would be for the Johns Hopkins Legacy Gift website made available by Johns Hopkins Pathology and for use during presentations. Information provided would include an explanation of how cancer develops, past cancer research, how autopsy contributes to research, what kinds of studies can be done, and why and how the rapid autopsy procedure is done.

Preliminary research began with a review of how patients and their families receive information about the Legacy Gift Program and what information would be most beneficial. Consultation with Dr. Hooper revealed that patients are informed of the program typically through a conversation with their oncologist but also from support groups and individual research. Those who are informed by their oncologist are made aware of and directed to the Legacy Gift website for additional information. Individual discussions with a physician assistant from oncology and a pediatric oncologist also informed what content to focus on for patient education.

The Johns Hopkins Legacy Gift Website provides some of the information requested for the educational resource. This includes some information on the type of research done, why rapid autopsies are performed, a little about the process of participation and cost to the family (Johns Hopkins University n.d.). There is also a link to frequently asked questions that addresses additional topics related to participation and addresses concerns of the effects of the procedure regarding the amount of time the family has with their loved one after their passing and how it affects the timeline for the funerary proceedings (Johns Hopkins University n.d.). Links to learn about those

involved in the program, publications, related media, related links, contact information, and a memoriam are also available (Johns Hopkins University n.d.). Visuals currently available are primarily photographs of those who are involved in the program. The new resource will greatly expand on the information currently available and include more patient directed information. Figure 1. provides an outline of the content for the new resource.

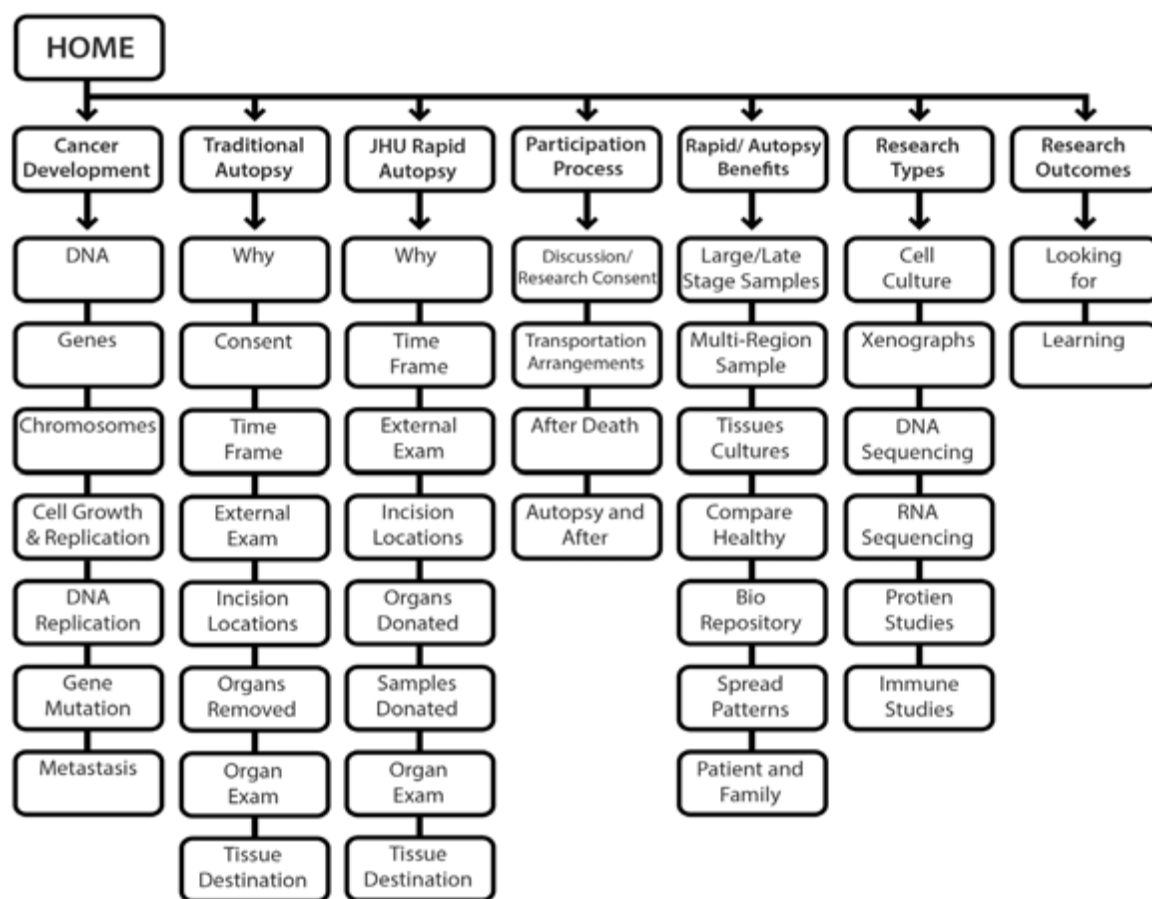


Figure 1. Flowchart of the information for the educational resource.

Observation of a Rapid Autopsy

One rapid autopsy procedure performed by Dr. Hooper was observed. The procedure was partially modified. Anatomy typically removed superior to the clavicles

such as the tongue and thyroid was left in place as were the eyes. Observing the procedure was imperative for understanding the procedural steps, the environment, the instruments used, and how they each differ from a standard autopsy. The observed differences from a standard autopsy are:

- starting of the procedure within 6 hours of death,
- use of sterile gloves and scalpels,
- sterilization of the skin at the incisions,
- removal of multiple samples of tumor tissue and blood samples while all organs were in situ, and
- the presence of researchers to immediately collect and process the samples.

Research for Narration and Design

Research for the informational content of the narration began with a review of cancer biology, past cancer research and the current direction of cancer research involving, prevention, diagnosis and personalized treatment. Primary resources where the National Institutes of Health National Cancer Institute website, Frederick O. Stephens and Karl Reinhard Aigner's "Basics of Oncology", Wei Wu's and Hani Choudhry's "Next Generation Sequencing in Cancer Research, Volume 2 From Basepairs to Bedsides", and the film "Cancer: The Emperor of All Maladies". These resources where used to develop the sections about cancer development and research types.

Information about the process of participating was gathered from an outline of the process of participation provided by Dr. Hooper and copies of the rapid research consent and the autopsy consent. These resources were used to develop the content for the

sections addressing, autopsy, rapid autopsy, the participation process, benefits, research type, and research outcomes. Papers published by researchers from the Johns Hopkins Rapid Autopsy program and other rapid research programs were also used to develop the sections regarding the benefits, research types, and research outcomes.

Multiple approaches of research were used to develop the language and look of the interactive. Influences came from a review of similar autopsy research donation programs resulting from a general online search and from a review of other body donation programs' approaches to web content. Patient, family, and provider opinion toward autopsy and specifically rapid autopsy was also investigated. Additional reviews of healthcare literacy, learning theory, and communication in healthcare influenced the language, style and complexity of art assets, tone and pace of narration, and the decision to present the material in sections and in multiple forms that can be displayed at the will of the user.

Definition of the Educational Resource

Considering that the educational tool is meant to be referenced by a diverse audience both in background and primary learning interests, it was decided to create interactive modules that would contain animation, narration, and written text (figure 2.).



Figure 2. Mock display of the interactive educational resource on the Johns Hopkins Legacy Gift website. Text is not intended to be read.

Each of the seven primary topics (cancer development, traditional autopsy, rapid autopsy, participation process, rapid autopsy benefits, research types, and research outcomes) would have their own interactive module. Upon clicking on the title, the module would display below. Each of the subcategories would be displayed as buttons and clicking on the button displays the associated animation and the text. The topics of the subcategories match the categories of the content outline (figure 1.). At the bottom of the subcategory

buttons, is a button to display all text for those who wish to view all of the information for each primary category at once.

Script

A completed draft of the script (Appendix: A) was developed from the content outline. Reading level was highly considered while drafting the script. Word, sentence, and paragraph length were monitored and shortened when changes could be made without altering the meaning. In the instance that medical jargon was used, the definition was also provided.

The goal was to provide information relevant to understanding the purpose and process of autopsy and rapid autopsy. The content was broken into categories and sub-categories. This was done to break the content into smaller sections to aid learning and, if desired, to allow users to review only information he or she finds appropriate for their needs. For those that prefer a base of knowledge that can be progressively added to, the information was organized in the sequence that each topic would be encountered (cancer development, learning about autopsy, participation, and outcomes). The script was subject to multiple reviews and edits by the project advisor Timothy Phelps and by Dr. Hooper.

Interactive Development

Hand Wire-framing

Interactive development began with hand drawn wireframes on paper to quickly map a variety of navigation steps on paper (figure 3.). This was important to work out the navigation of the interactive and to determine the steps that would have to be coded in the final interactive prototype.

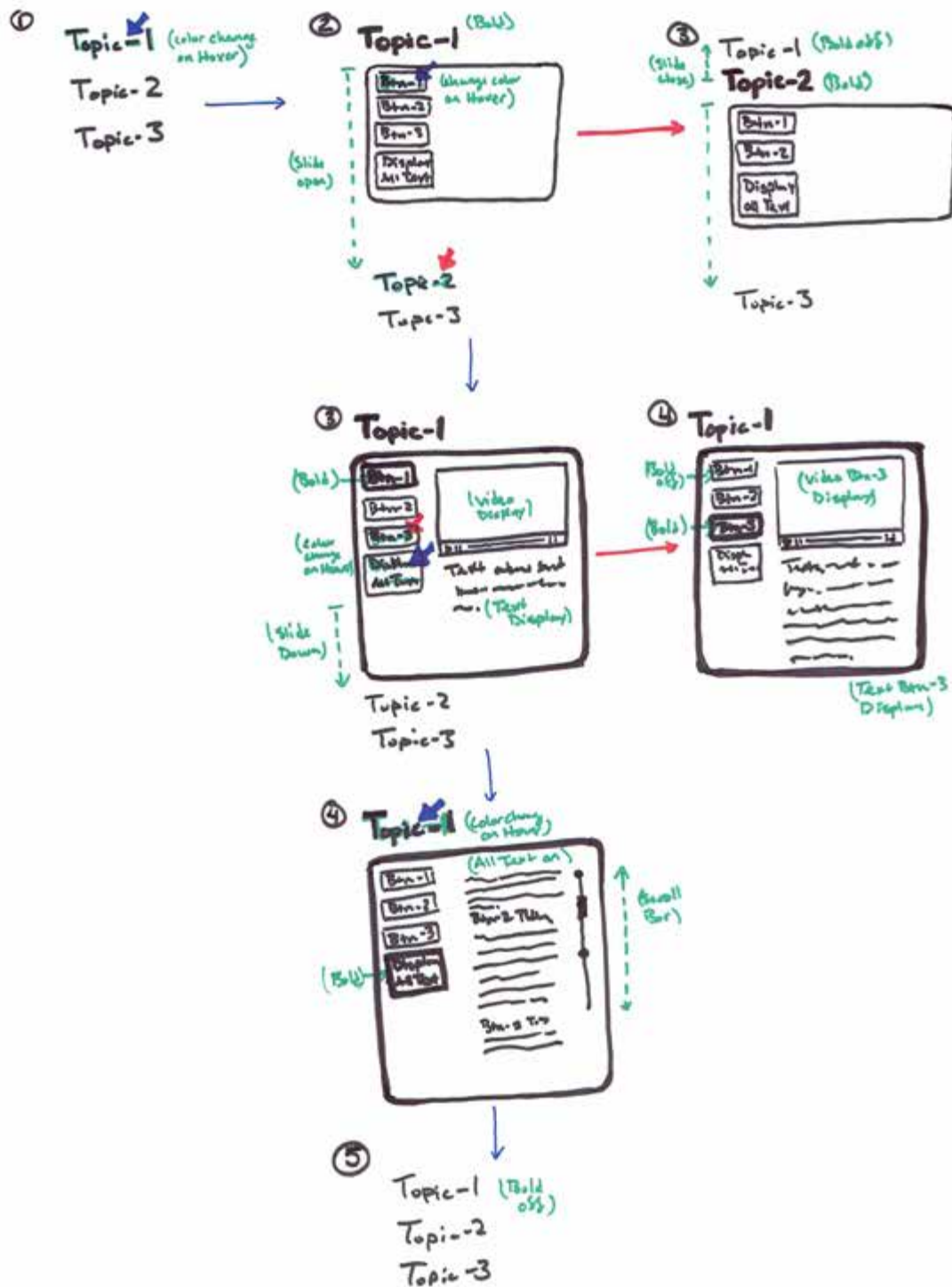


Figure 3. Hand drawn wire-frame used for the development of the final interactive prototype. Text is not intended to be read.

Navigation Prototyping in Axure RP Pro 7.0

Once a method of navigation was decided on, a wireframe prototype was developed using the program Axure RP Pro 7.0. This program was selected because it features an easy to use drag and drop widgets pane (figure 4.) to create the pages and a simplified interactions pane (figure 5.) to set up the links between the pages. It also allows the prototype to be previewed in a browser window during development and can generate a URL that can be shared with reviewers for user testing.

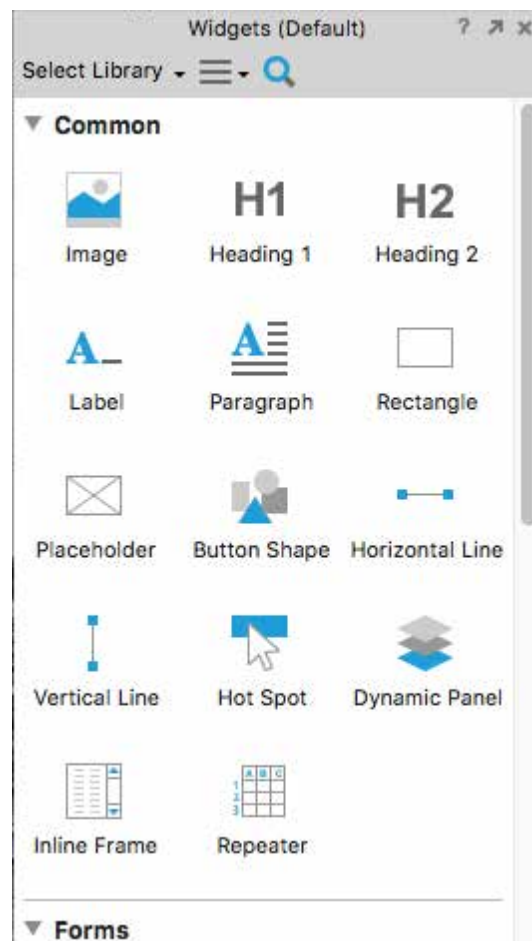


Figure 4. Axure RP Pro 7.0 widgets pane.

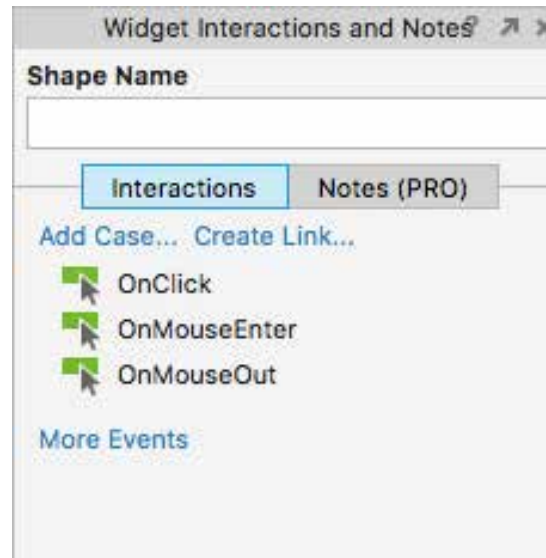


Figure 5. Axure RP Pro 7.0 interactions pane.

The primary widgets used were “button shape”, “rectangle”, and “image” found under “Common” and “text area” available under “Forms”. These widgets were used to design a total of 16 pages. All of the pages, with interactive buttons highlighted in green, can be viewed in Appendix B. The pages included a “Home” page with two child pages. These child pages titled “Rapid Procedure” and “Participation Process” each contained nine and four child pages respectively. A new page was required for each change in screen display. This would include changes such as going from the home screen with all buttons collapsed to having one button expanded after being clicked. To indicate that a button is clicked, the button becomes bolded on the new page. This effect was created by changing the font to bold and increasing the line width of the button (figure 6.).

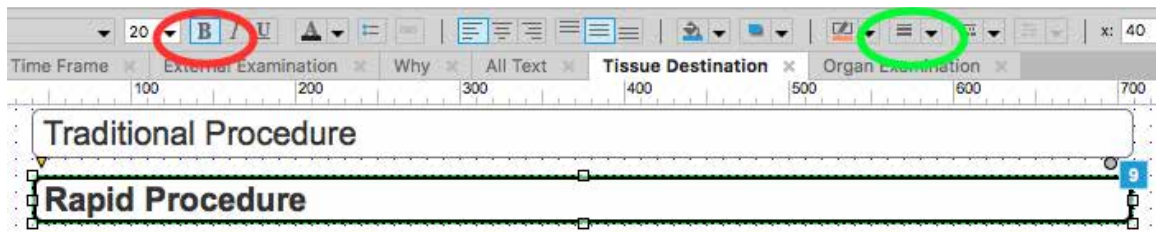


Figure 6. Formatting for the clicked button. The “Traditional Procedure” un-clicked button is shown at regular text and line thickness. The “Rapid Procedure” clicked button shows the text and line in bolded form. The red oval indicates the icon to make the text bold and the green oval indicates the icon used to increase the line thickness.

Interactions were applied to buttons so that when the button is clicked a new page will display. This process was completed with the use of the interactions pane. To apply and interaction between pages, a button on a page was selected (figure 7.) then “create link” was selected from the interactions pane (figure 8.). This would reveal the option to type in the desired page to which the button will link or to select the page from the dropdown (figure 9.). Once the page was selected the interaction was created (figure 10.) and the link between the pages was established. The buttons were tested by previewing the interactive in a web browser.

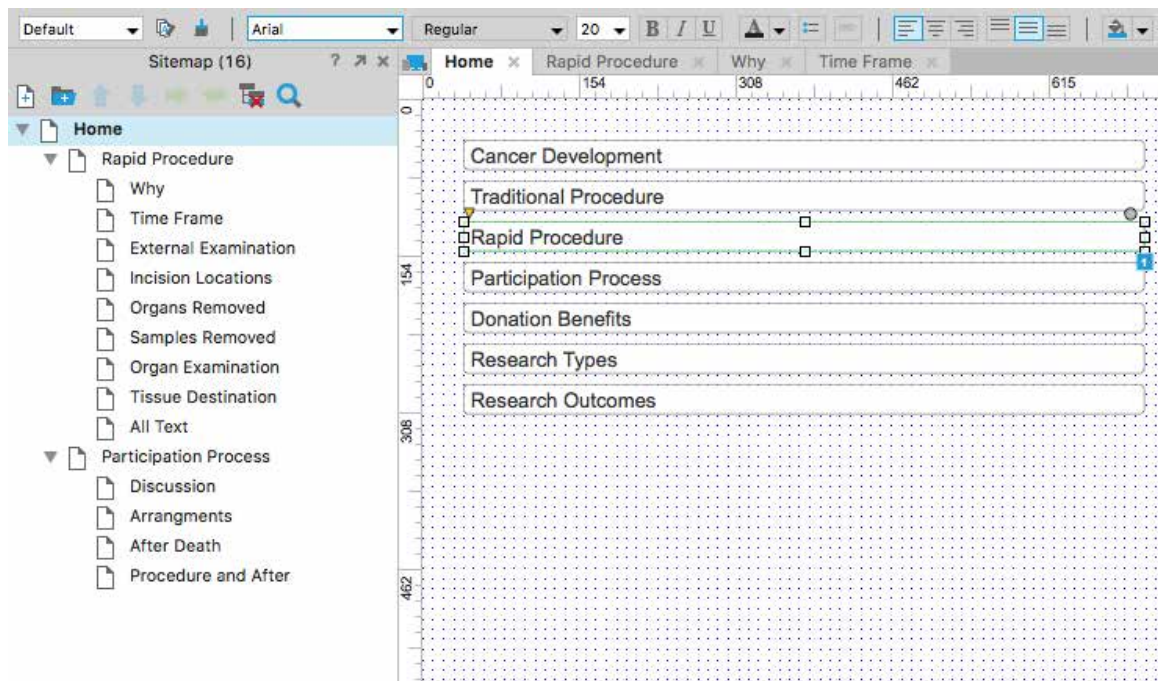


Figure 7. The “Rapid Procedure” button is selected on the “Home”page.

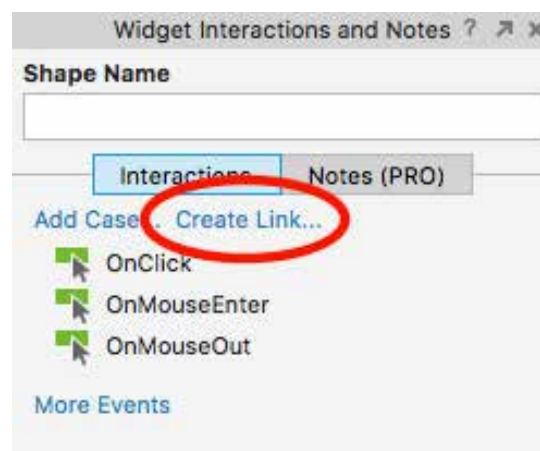


Figure 8. Adding an interaction with the interactions pane. The oval indicates the option selected.

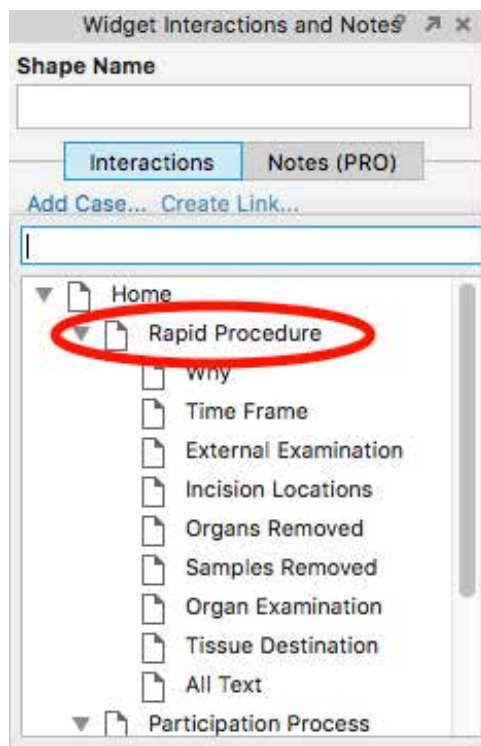


Figure 9. Adding an interaction to the “Rapid Procedure” page indicated by the red oval.

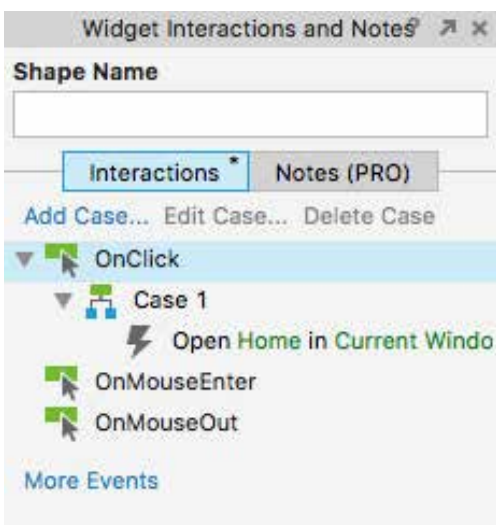


Figure 10. A new interaction was added to the “Rapid Procedure” button on the “Home” page. When the “Home” page is previewed in the browser, the “Rapid Procedure” button can be clicked and will display the “Rapid Procedure” page.

The navigational links were created for all of the “Rapid Procedure” module and part of “Participation Process” module. This was done to work out the navigational flow within the individual module and the interaction when the title for a module is clicked while another module is open.

An overview of the navigation begins when one of the buttons from the primary menu (figure 11.) is clicked. This will open the interactive module for that button (figure 12.). If that same button from the primary menu is clicked again while the module is open the module will close (figure 11.). Clicking a button from the secondary menu in the module will open the animation and text for that button (figure 13.). Clicking another button from the secondary menu will replace the animation and text with its own (figure 14.). Clicking on another button from the primary menu while a module is open will close that module and open the module for the newly selected button (figure 15.).



Figure 11. Axure interactive prototype primary menu.

Cancer Development

Traditional Procedure

Rapid Procedure

Why

Time Frame

External Exam

Incisions

Organs Donated

Samples Donated

Organ Exam

Tissue Destination

Display All Text

Participation Process

Donation Benefits

Research Types

Research Outcomes

Figure 12. “Rapid Procedure” module opened displaying the secondary menu within the module.

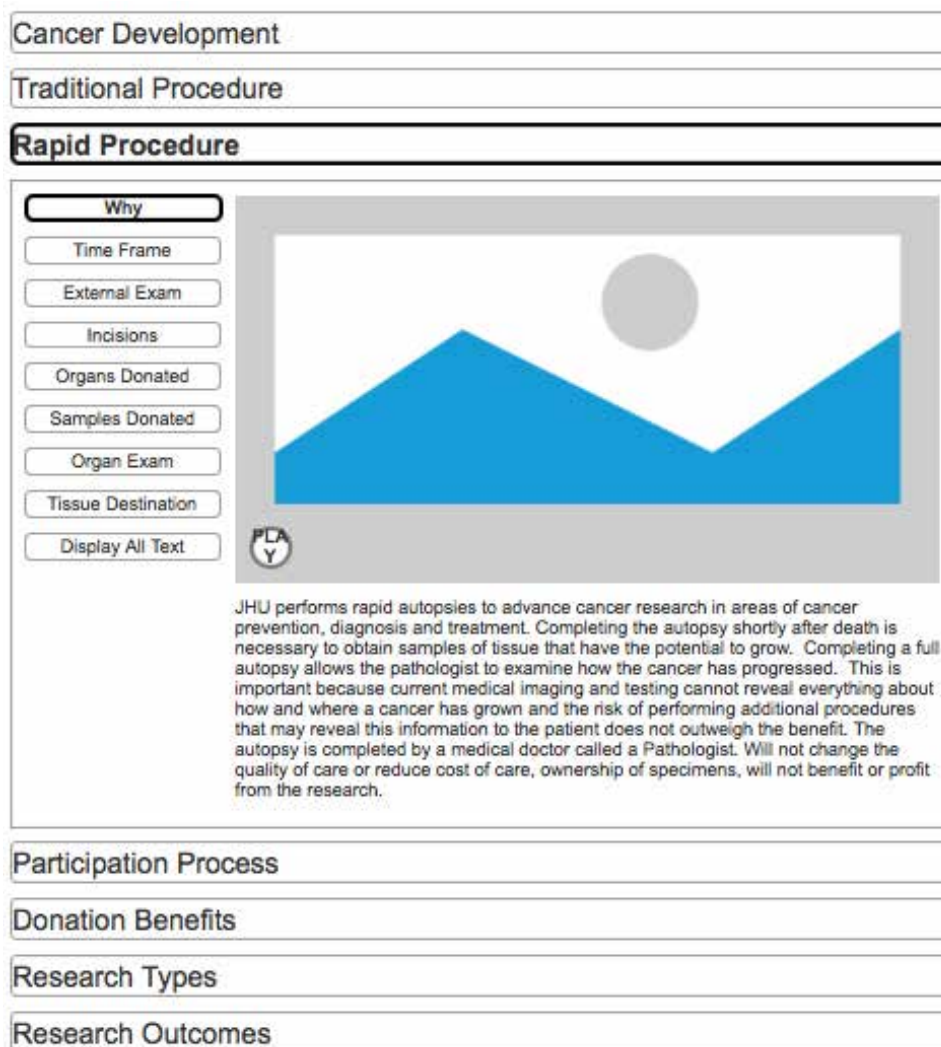


Figure 13. “Why” button clicked in the secondary menu. The animation and text for “Why” are displayed.

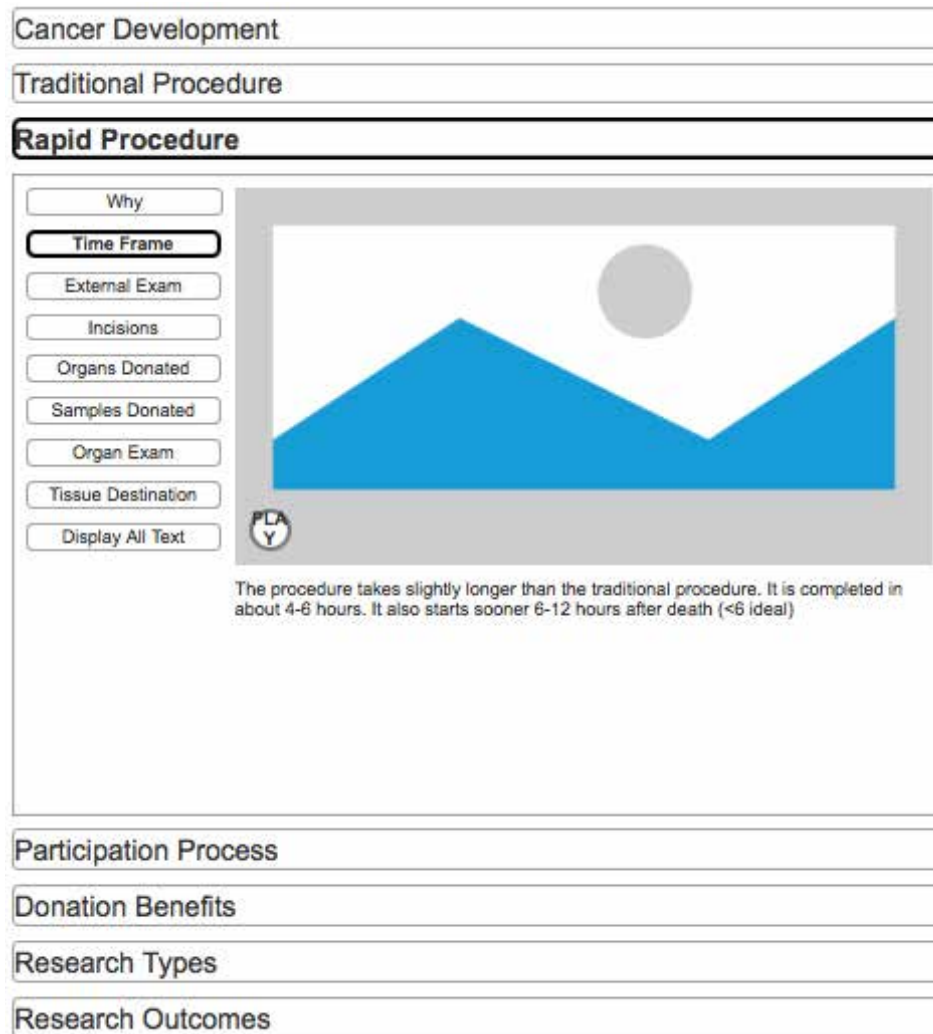


Figure 14. “Time Frame” is clicked in the secondary menu. The animation and text for “Why” are replaced by the animation and text for “Time Frame”.

Cancer Development
Traditional Procedure
Rapid Procedure
Participation Process
<div>Discussion</div> <div>Arrangements</div> <div>After Death</div> <div>Procedure and After</div>
Donation Benefits
Research Types
Research Outcomes

Figure 15. A second module is selected. An open module will close if another topic from the primary menu is selected. The newly selected module will then open.

After the prototype was created, it was uploaded to axureShare. This generated a URL that could be shared. The URL was provided to Dr. Jody Hooper for review and approval.

Prototype in Adobe Edge CC 2015

Adobe Edge CC 2015 was used to develop the final prototype to establish the look and the coding that would be standard for each module. In addition to prototyping in Axure, style sheets were also created. These mock web pages were created in Adobe Photoshop CC 2015 with the use of screen shots from the Johns Hopkins Legacy Gift website. These style sheets were evaluated by Timothy Phelps and Dr. Jody Hooper. The preferred style sheet (figure 2.) was used as a model for the development of the assets in Edge Animate.

The width of the stage was determined based on the space available on the website and the height by the space needed to display the animation over the text. The size is 700 x 550 pixels. To prevent any content outside of the stage from being visible, the “Overflow” was set to “hidden”. The “Composition Class” was then changed to “RapidAutopsyInteractive” so the HTML element ID can be more easily distinguished between each of the interactive modules. The Legacy Gift website is not currently responsive. However, responsive design is a growing trend as users spent more time accessing the internet on alternative devices such as phones and tablets. If future redesign of the website takes this direction, “Responsive Scaling” can be selected and the parameters set to affect both height and width.

The use of color was a major component in keeping the interactive modules harmonious with the existing website. To match the exact colors, a screenshot of the website was opened in Photoshop and the color picker tool was used to get the exact RGB numbers (figure 16.) Three shades of blue that were identified as light, medium, and dark in color (figure 17.). The RGB numbers were then entered in the color picker in

Edge Animate and each color was added to the palette (figure 18).

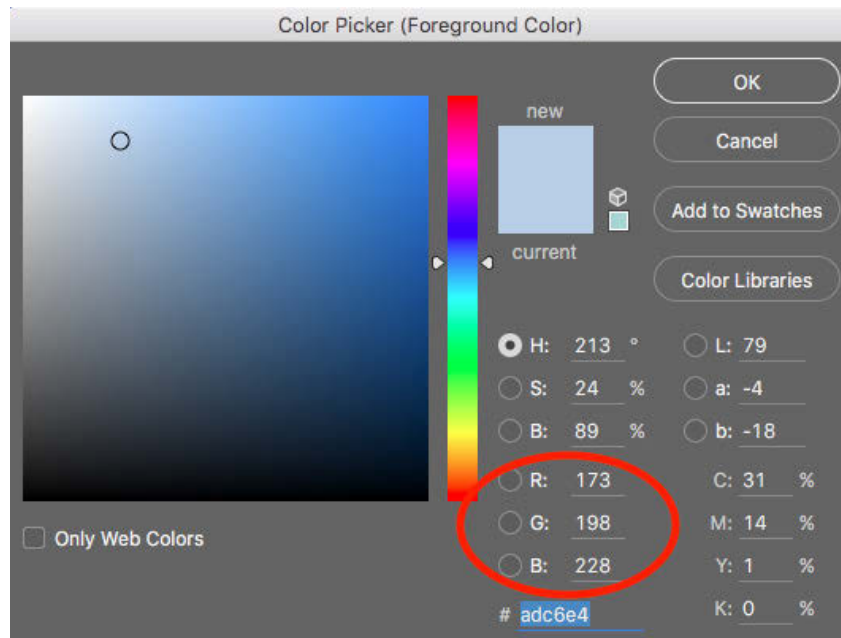


Figure 16. The color picker window in Adobe Photoshop CC 2015. The red oval indicates the location of the RGB numbers.



Figure 17. Three blues were directly selected from the Legacy Gift website. A light blue from the menu containing links about the program and its contributors. A medium blue was selected from the text in that same menu. A dark blue was selected from the web banner

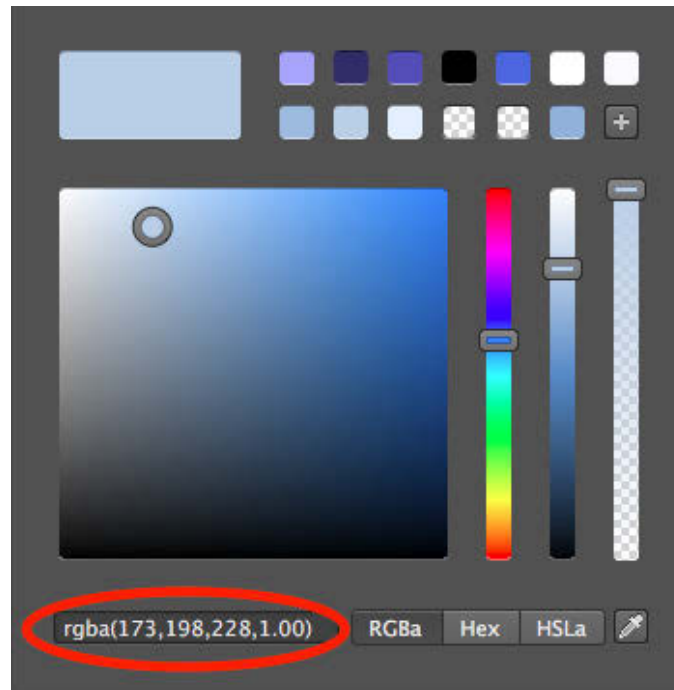


Figure 18. The color picker window from Adobe Edge Animate CC 2015. The red oval indicates where the RGB numbers from Photoshop were entered.

These colors were used to create the buttons. Derivatives of these colors, in addition to white and black, complete the color pallet for the interactive. The derivatives were created and added to the pallet by adjusting the “lightness” and “hue”. A lighter version (RGBA 221, 236, 255, 1.00) of the light blue was used for the background. The light blue is the primary color of the unclicked version of the buttons. Two additional (lighter and darker) derivatives (RGBA 249, 250, 254, 1.00 and RGBA 141, 175, 217, 1.00 respectively) were created to make the highlight and shadow colors of the un-clicked button (figure 19.).



Figure 19. The unclicked (A) and clicked (B) version of the “Why” button.

The light blue was used for the unclicked buttons so it would match the existing menu and indicate the location of a link to additional information. The medium blue was used for the text on the unclicked buttons. Again, this was done to match the existing menu and indicate a link. The dark blue was used as the primary color of the clicked buttons. Lighter and darker derivatives (RGBA 149, 152, 255, 1.00 and RGBA 31, 33, 90, 1.00 respectively) were again created for the highlight and shadow of the clicked buttons (figure 20.). This dark color creates a strong contrast to the background and unclicked buttons clearly indicate the button is selected. White was used for the text on the button to make it easy to read. Black was selected for the remaining text in the interactive.

With the exception of importing the video, all components of the interactive were created using the “rectangle tool”, “rounded rectangle tool”, and “text tool” located in the “tools” menu. To create the background, the opacity of the stage was set to 0 and the rounded rectangle tool was used to create the background shape. The corners were set to 15 pixels to match the rounded corners of the existing menu.

A total of nine buttons were created within the interactive with nested symbols and elements (figure 20.). Nesting was required to create a clicked and unclicked version of each button and to create the look of rounded edges. Each button was made by using the rounded rectangle tool to generate a shape element 191 pixels in width and 35 pixels in height with the corners set to five pixels. The opacity was then set to 0 and the element converted to a symbol (modify > convert to symbol). On the stage for the new button symbol (figure 21.), another rounded rectangle element of the same dimensions was created and duplicated (figure 22.).

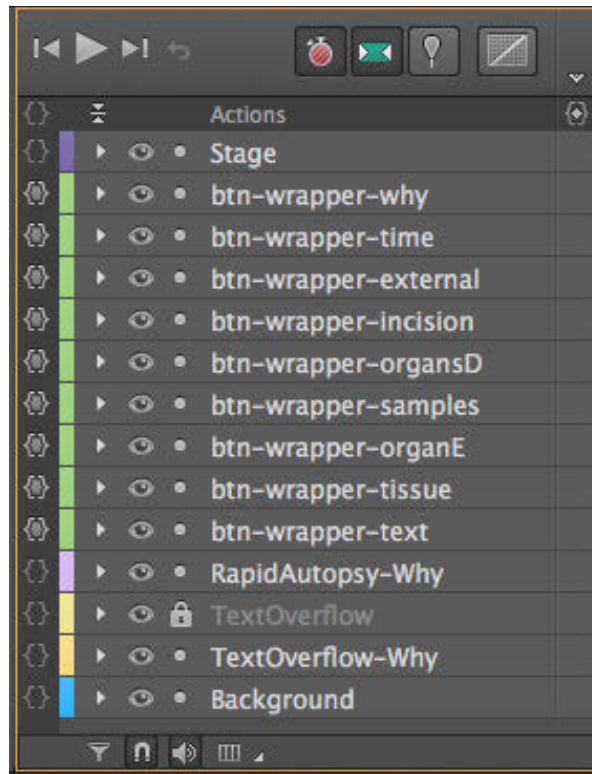


Figure 20. Symbols and elements on the main stage in Adobe Edge Animate CC 2015 listing.

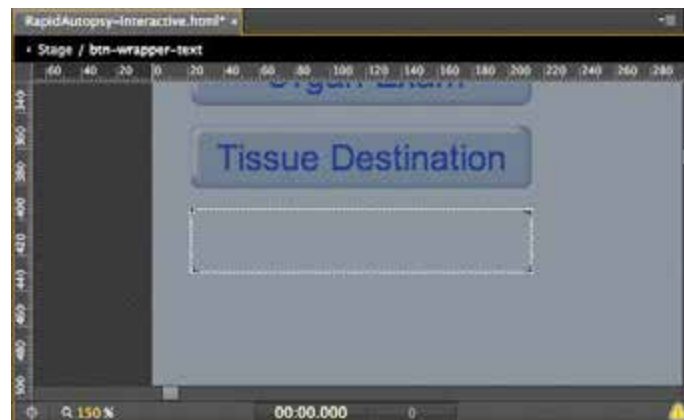


Figure 21. The stage for the symbol “btn-wrapper-text” in Adobe Edge Animate CC 2015.

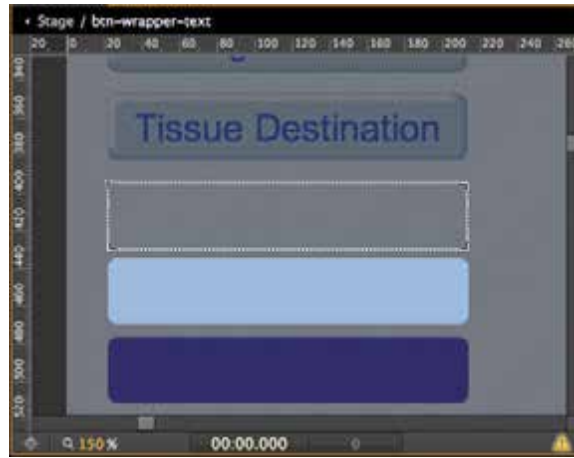


Figure 22. Shadow layers of the clicked and unclicked version of the buttons on the stage for the symbol “btn-wrapper-text” in Adobe Edge Animate CC 2015.

Their colors were set to the shadow colors for the clicked and unclicked buttons. Next a rounded rectangle, 187 pixels in width and 31 pixels high with the corners set to 5 pixels, was created. The blur filter was then set to 1 pixel and the element was duplicated. Each was set to the highlight colors for both versions of the button and then positioned in the upper left corner of their respective shadow element (figure 23.).

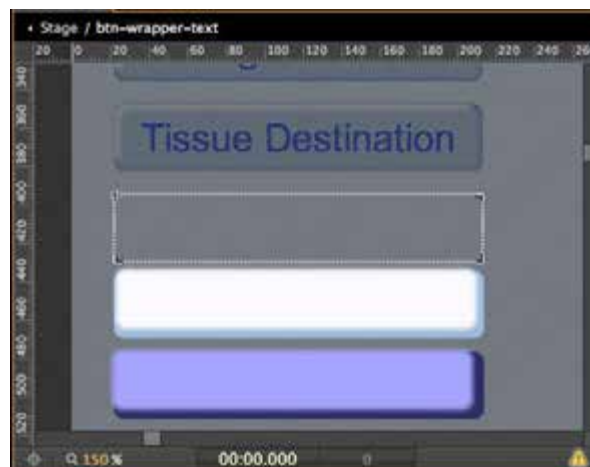


Figure 23. The highlight layers of the clicked and unclicked version of the buttons on the stage for the symbol “btn-wrapper-text” in Adobe Edge Animate CC 2015.

The highlight elements were then duplicated, changed to the light blue and dark blue colors, and centered within the shadow shape (figure 24.). A text layer was then added with the font set to Arial, 20 pixels, normal weight, and the color set to the medium blue for the unclicked button. For the clicked button, the text layer was duplicated and weight set to bold color changed to white (figure 25.). The layers for both the unclicked and clicked buttons were grouped and converted to symbols (figure 26.).

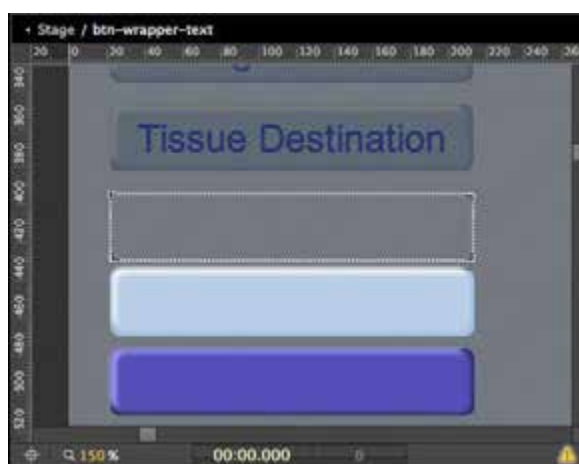


Figure 24. The main fill layers of the clicked and unclicked version of the buttons on the stage for the symbol “btn-wrapper-text” in Adobe Edge Animate CC 2015.

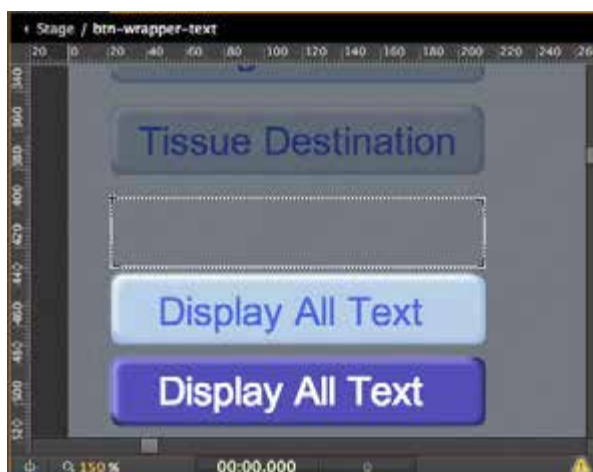


Figure 25. The text layers of the clicked and unclicked version of the buttons on the stage for the symbol “btn-wrapper-text” in Adobe Edge Animate CC 2015.

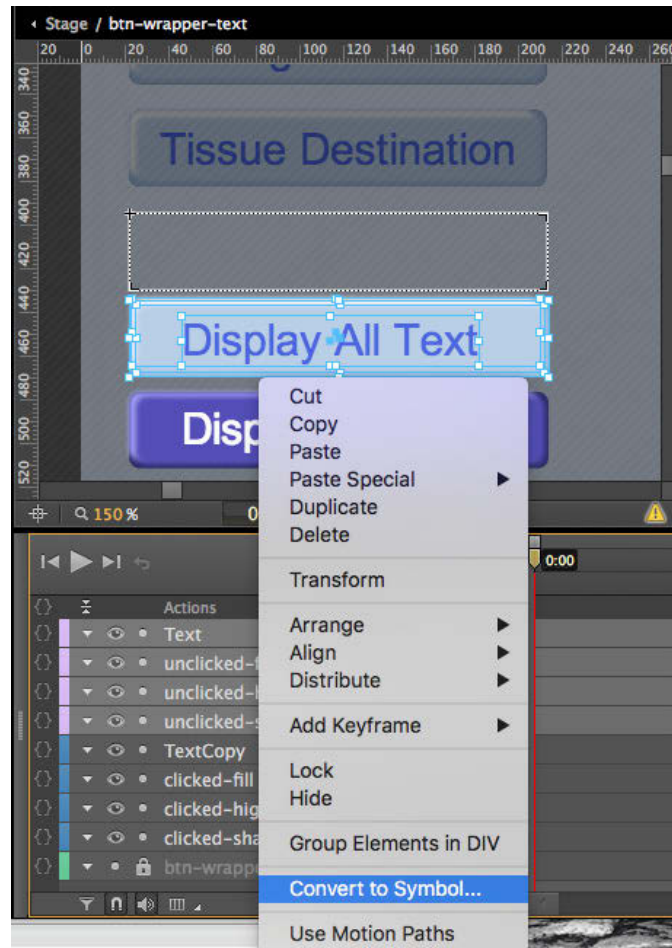


Figure 26. The layers of the unclicked version of the button selected and being converted to a symbol on the stage for the symbol “btn-wrapper-text” in Adobe Edge Animate CC 2015.

To indicate the buttons contain links, the cursor style for each button symbol on the main stage was set to “pointer” (properties > cursor > pointer). Also, when the mouse scrolls over any of the unclicked buttons, the button enlarges. To create this effect, the scale of the shape elements was key framed to expand from 100% to 105% and back. This was not applied to the text because the scale change caused the text to become blurry. Three triggers (sym.stop();, sym.stop();, and sym.stop(“off”); respectively) and three labels (“stop”, “mouseOver”, and “mouseOut” respectively) were added to control the playback (figure 27.).

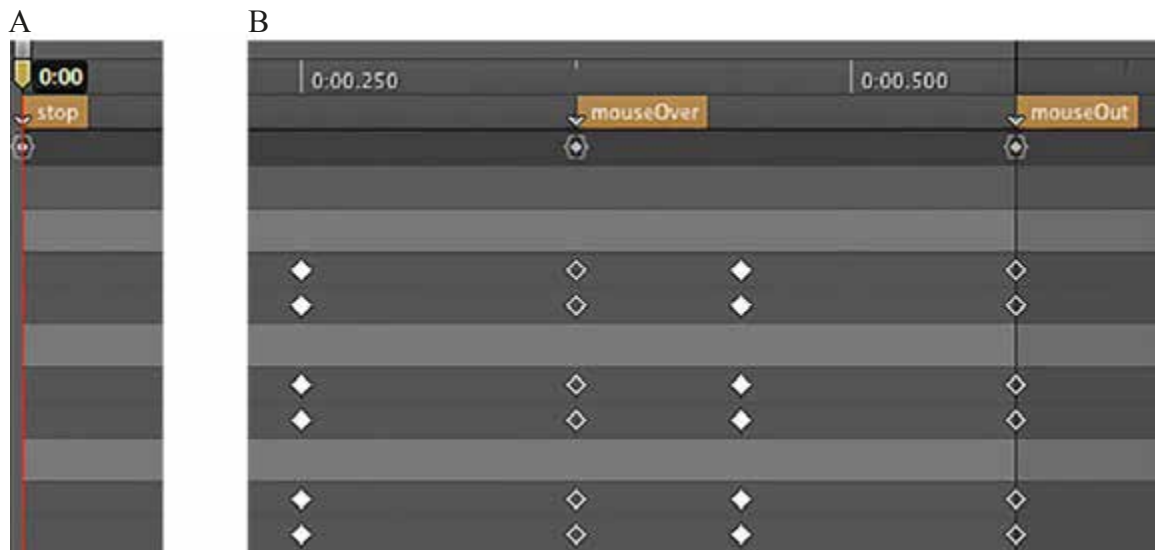


Figure 27. The timeline with triggers, labels, and key frames for the symbol “btn-OPEN-text” in Adobe Edge Animate CC 2015. (A) Trigger (sym.stop();) and “stop” label”. (B) Triggers (sym.stop();) and (sym.stop(“off”);) and “mouseOver” and mouseOut” labels.

For the prototype, the “Why” and “Display All Text” buttons were populated with content. This included an animation and text. The animation, saved as an mp4, was imported to the library, added to the main stage and its display set to “off”. Coding for the “Why” button would be used to turn the display “on” when the “Why” button was clicked. Two text boxes were created, one for the text to populate “Why” and the other for “Display All Text”. Each textbox was made by creating a rectangle element and setting the opacity to 0. Their sizes were 450 x 509 pixels and 450 x 238 pixels. This element was then converted to a symbol and the overflow set to scroll (properties > overflow > scroll). After entering the new stage, a text box same width was created for the actual text. The length varied to fit the text. The font was set to Arial, 18 pixels, normal weight, and black. Titles within “Display All Text” were changed to 22 pixels and bold.

Expressions in Adobe After Effects are based on javascript. Expression code was applied to each of the nine buttons and consisted of series of “play”, “hide”, “show”, and

“if” statements. The mouse over (figure 28.) and mouse out (figure 29.) events required a play function set to play from the corresponding label.

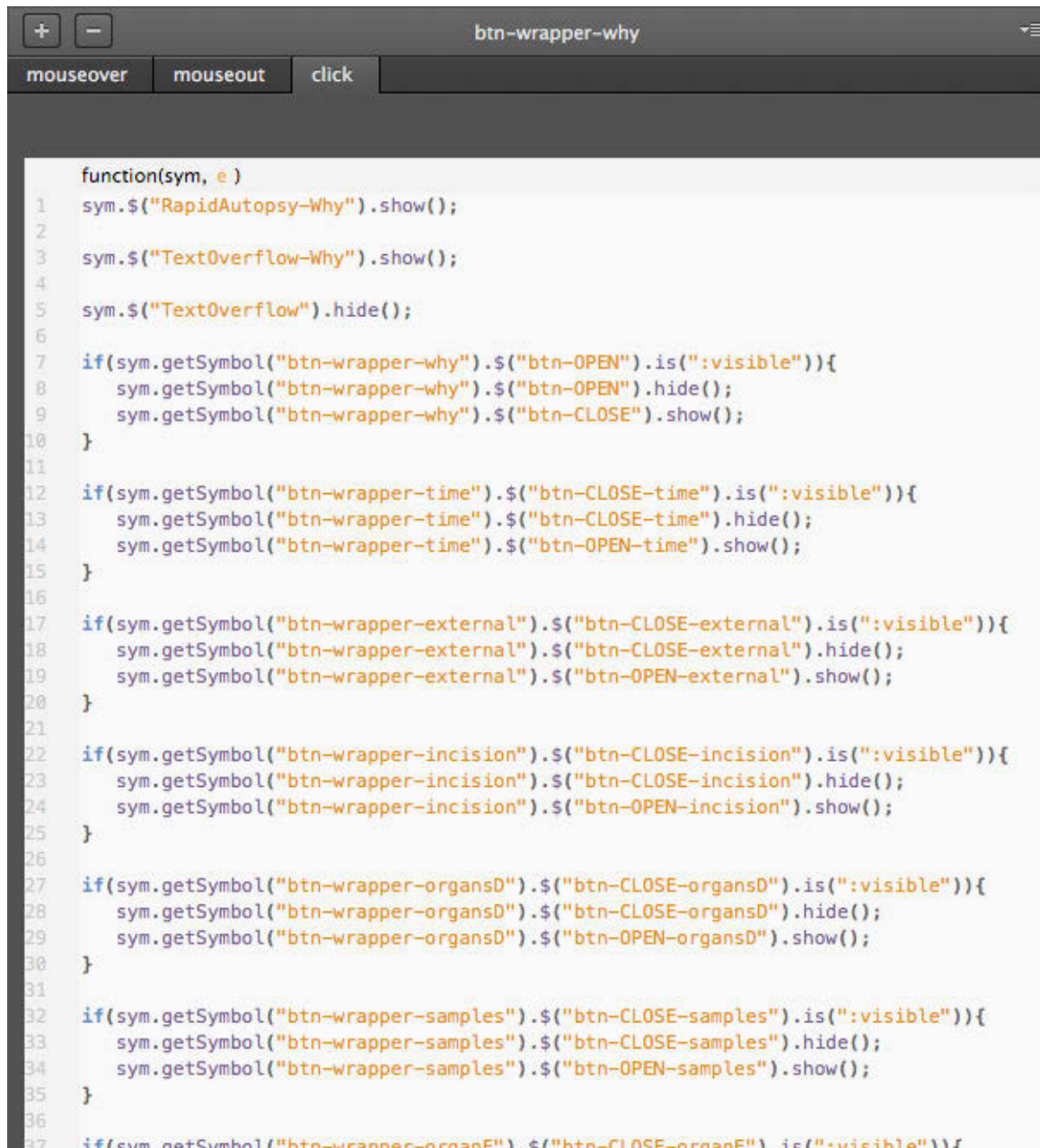


Figure 28. Code for mouse over event in Edge Animate CC 2015. Causes the button to enlarge to 105%. This function was applied to all buttons.



Figure 29. Code for mouse out event in Edge Animate CC 2015. Causes the button to reduce to 100%. This function was applied to all buttons.

For the click event in each button, hide and show statements were used to turn the display of that button’s contents “on” and the display of the contents of the other buttons “off”. For example, the “Why” button required “show” statements to turn the display of that topic’s animation and text box “on” and a “hide” statement to turn the “Display All Text” textbox “off” (figure 30.). A series of “if” statements was then written to change the display of the buttons. Continuing with the same example, the “Why” button required an “if” statement checking to see if the unclicked version of that button was “visible” and if it is to hide it and show the clicked version. This statement was then modified to check the visibility of the remaining buttons and turn any clicked version off and the unclicked versions on (figure 30.).



```

function(sym, e )
1  sym.$("RapidAutopsy-Why").show();
2
3  sym.$("TextOverflow-Why").show();
4
5  sym.$("TextOverflow").hide();
6
7  if(sym.getSymbol("btn-wrapper-why").$("btn-OPEN").is(":visible")){
8      sym.getSymbol("btn-wrapper-why").$("btn-OPEN").hide();
9      sym.getSymbol("btn-wrapper-why").$("btn-CLOSE").show();
10 }
11
12 if(sym.getSymbol("btn-wrapper-time").$("btn-CLOSE-time").is(":visible")){
13     sym.getSymbol("btn-wrapper-time").$("btn-CLOSE-time").hide();
14     sym.getSymbol("btn-wrapper-time").$("btn-OPEN-time").show();
15 }
16
17 if(sym.getSymbol("btn-wrapper-external").$("btn-CLOSE-external").is(":visible")){
18     sym.getSymbol("btn-wrapper-external").$("btn-CLOSE-external").hide();
19     sym.getSymbol("btn-wrapper-external").$("btn-OPEN-external").show();
20 }
21
22 if(sym.getSymbol("btn-wrapper-incision").$("btn-CLOSE-incision").is(":visible")){
23     sym.getSymbol("btn-wrapper-incision").$("btn-CLOSE-incision").hide();
24     sym.getSymbol("btn-wrapper-incision").$("btn-OPEN-incision").show();
25 }
26
27 if(sym.getSymbol("btn-wrapper-organsD").$("btn-CLOSE-organsD").is(":visible")){
28     sym.getSymbol("btn-wrapper-organsD").$("btn-CLOSE-organsD").hide();
29     sym.getSymbol("btn-wrapper-organsD").$("btn-OPEN-organsD").show();
30 }
31
32 if(sym.getSymbol("btn-wrapper-samples").$("btn-CLOSE-samples").is(":visible")){
33     sym.getSymbol("btn-wrapper-samples").$("btn-CLOSE-samples").hide();
34     sym.getSymbol("btn-wrapper-samples").$("btn-OPEN-samples").show();
35 }
36
37 if(sym.getSymbol("btn-wrapper-organE").$("btn-CLOSE-organE").is(":visible")){

```

Figure 30. Code for the click event statements for “Why” in Edge Animate CC 2015. Not all of the if statements are captured in the window.

Storyboards

Storyboards for each topic under the “Rapid Autopsy” section were completed.

A standard reusable six-frame storyboard template was created in Adobe Illustrator CC 2015. It was exported as a .tif file and brought into Adobe Photoshop CC 2015 to complete the actual storyboards. All of the sketches, video, and audio notes were completed in Adobe Photoshop CC2015. This method was selected over hand drawing for the efficiency of being able to quickly duplicate and manipulate repeated imagery. Text was written by hand to keep all the text on one layer instead of in multiple textbox layers. This prevented approximately an additional seven layers per storyboard. As there are a total of 28 storyboards (Appendix: C), this format was imperative for reducing the overall layer count of the document and reducing document size, which contributed to the efficiency of the overall workflow. All of the storyboards were created in one document. This was done for the ease of being able to navigate to different art assets previously created. To maintain ease of navigation, the layers were organized into folders. Primary folders were titled by the name of the subsection (figure 31).

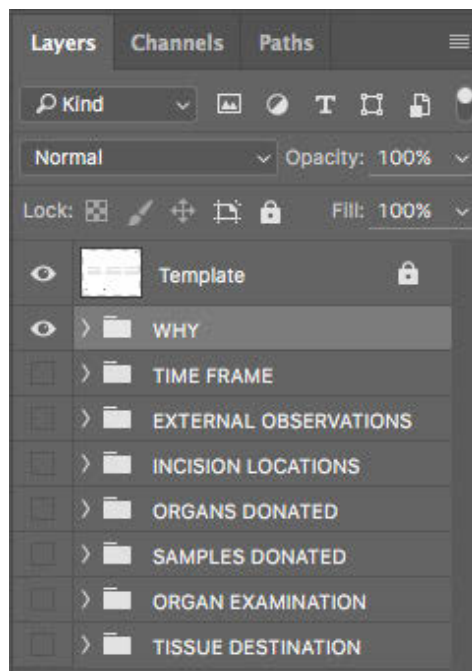


Figure 31. Primary folders titled by each animation in the layers panel in Adobe Photoshop CC 2015.

Each primary folder contained a text title layer a notes layer and subfolders for the individual pages (figure 32). Each page folder contained a notes layer, folders for each frame containing the art assets, and a layer of white. This allowed art elements to be maintained on separate layers (figure 33, figure 34). Total file size at 11” x 8.5” and 150 dpi is 28.7 MB. Color was only added when it offered support to the information being conveyed.

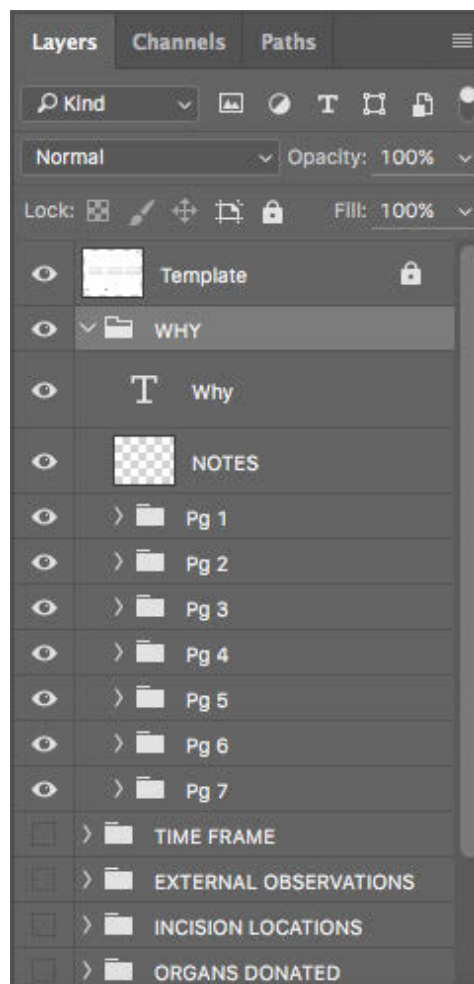


Figure 32. Nested layers and secondary folders labeled by each page of the storyboard in the layers panel in Adobe Photoshop CC 2015.

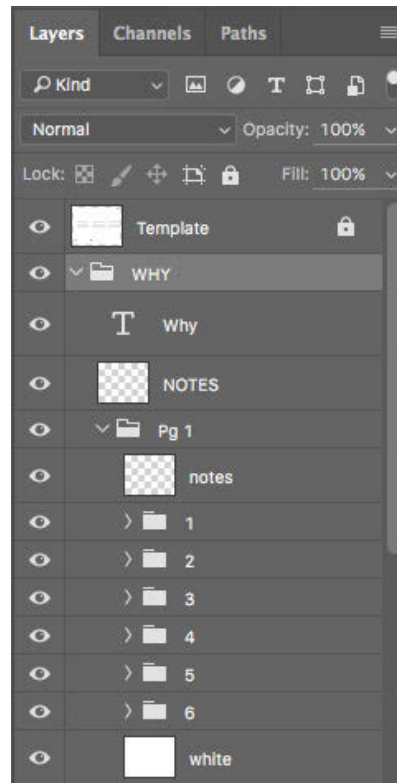


Figure 33. Nested layers and tertiary folders labeled by each frame of the storyboard page in the layers panel in Adobe Photoshop CC 2015.

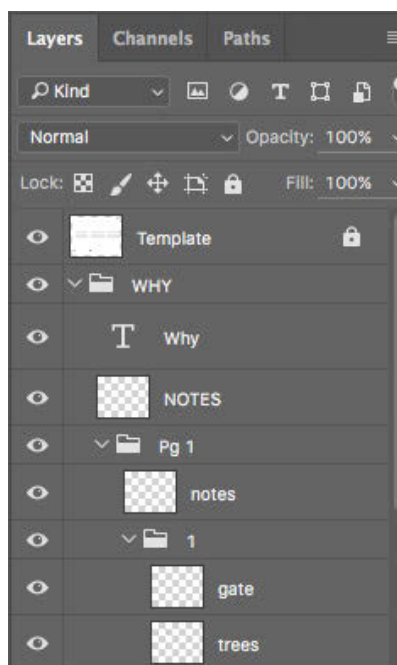


Figure 34. Nested layers of each frame in the layers panel in Adobe Photoshop CC 2015.

For the first few storyboards the recording of the script was timed using the Apple iPhone 5 “clock” application and the total time recorded on the storyboard. Then the individual lines for each scene were timed and recorded. This served to get a sense of the pacing of the animation and how much movement could be included in each scene.

The style of the sketching and art assets were kept similar to the intended look for the final art assets. Although initially this is more time consuming, this was done to provide a better sense of the final animation during the review process and reduce the need for revisions later in development. This also served to speed up the creation of the final art assets as some of the sketches could be used as a base to make the final assets. The storyboards went through multiple stages of review and editing by advisor Timothy Phelps and by Dr. Jody Hooper.

Recording

The audio was recorded and edited with Adobe Audition CC 2015 on 2011 MacBook pro. The original recording produced a 44100 Hz and 32 bitrate WAV file. A series of edits were then made to the audio file. First, noise reduction was applied after capturing the noise print at the beginning of the audio file. Minor echo was removed with dynamics processing (effects > amplitude and compression > dynamics processing). Auto pitch correction was applied. The volume was adjusted with effects > hard limiter > input boost. Then pops and clicks were removed by using auto heal in the spectral frequency display (figure 35.). The pace of the animation was slowed with effects > time and pitch > stretch and pitch > stretch and by adjusting the space between each sentence to 1.5 seconds. Finally, 36 markers were added to various time points to indicate the start and end of certain words so the animation would correspond to the flow of images. The final audio clip was one minute and fifty seconds long. The recording was done in a female voice and the pace reduced to similar patient education animations found online.

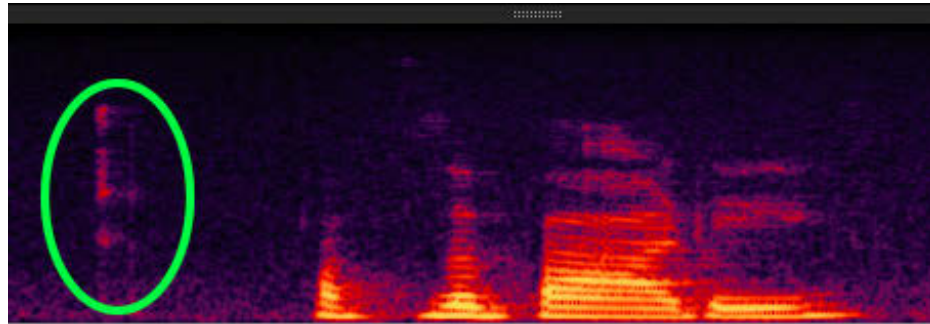


Figure 35. Spectral frequency display in Adobe Audition CC 2015. The green oval indicates a pop or click.

Art Assets

The assets for the animation were drawn in Adobe Photoshop CC 2015 at 300 ppi in the RGB color mode and exported as portable network graphics (png). Seventy-four imported art assets were used to complete the animation. For each image, the line work was completed first and the color fill was then added on a separate layer. This allowed the colors of each to be easily adjusted during development. These layers were merged and finalized after approval (figure 36.).



Figure 36. Brain art asset.

Organic shapes were drawn with the brush and eraser tools. For both tools the brush was modified from a soft round pressure brush by adjusting the scattering settings

(scatter to 94% and count to two), lowering the opacity to 80%, and setting the hardness to 50% (figure 37.).

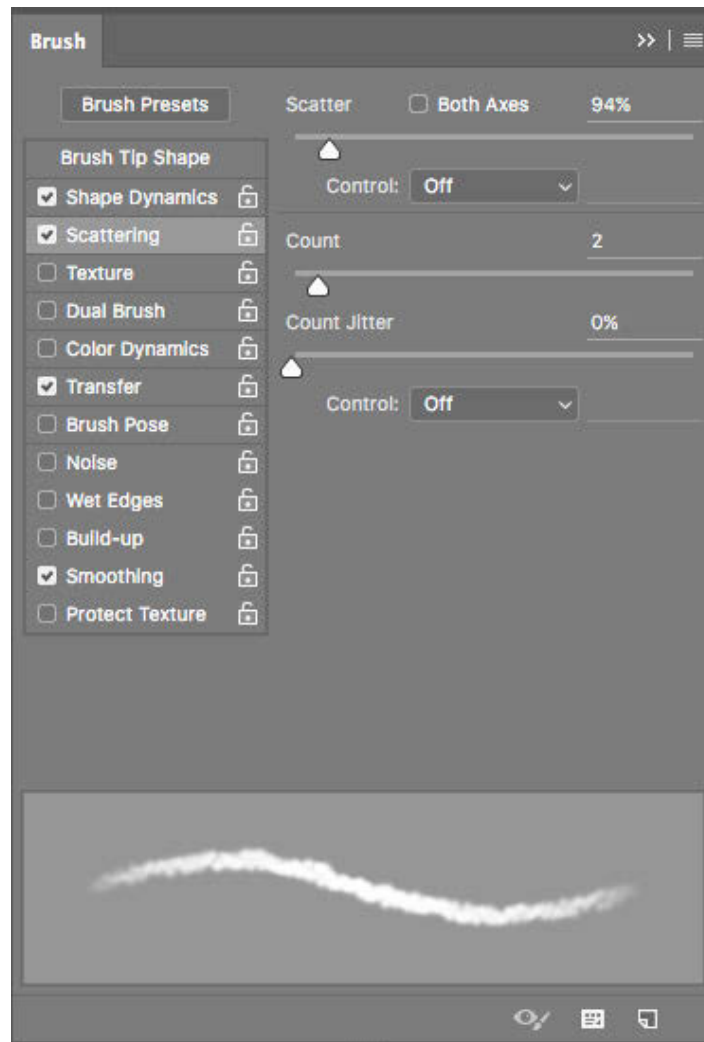


Figure 37. Brush scatter settings in Adobe Photoshop CC 2015.

This was done to mimic the look of a graphite line. It allowed for variation in line width and opacity and reduced the sharpness of the edges.

The shape tool was used for some of the non-organic forms. To generate a texture similar to the lines produced with the brush tool, a series of filters were applied and then the layers manipulated. The shape was produced with the foreground color set to black

and the background color set to white. Then the layer was rasterized and two filters were applied. First, a “Pointillize” filter set to 3 was applied then a “Gaussian Blur” filter set to 0.8. This was done to create a similar grainy texture but it causes the background of the line to fill with the background color (figure 38.).

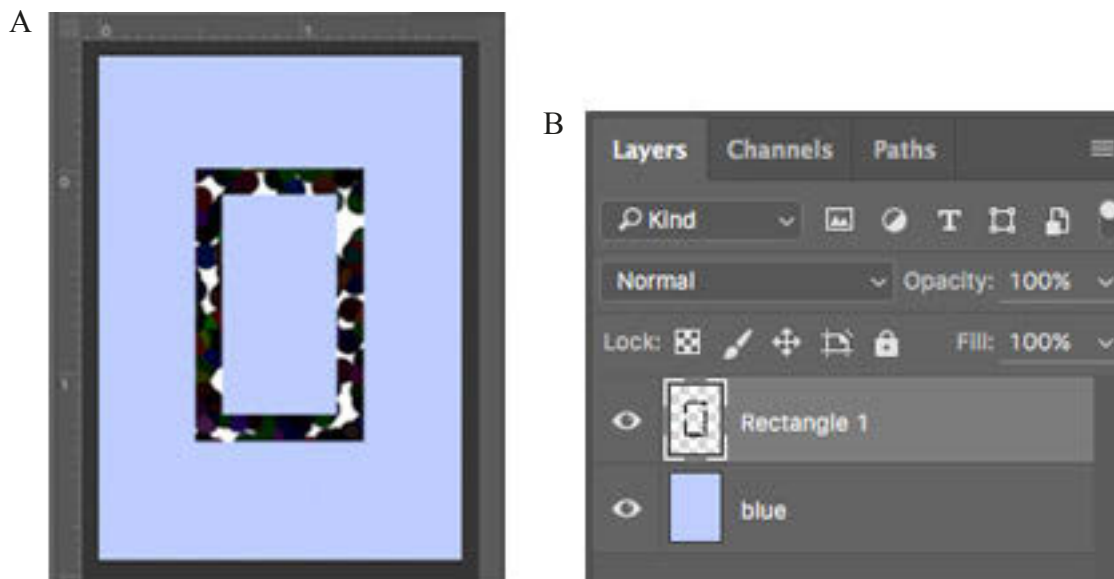


Figure 38. (A) A shape layer with the “Pointillize” and “Gaussian Blur” filters applied on a blue background. The cell size is set to 12 to make it easier to see. (B) Layers are a shape layer and a blue background layer.

Because the fill was set to white, it can be removed leaving only the black at various transparencies behind. Although, changing the blending mode to “multiply” will remove the white, the white will return when the layer is merged with another layer and when the file is saved if there is transparency behind it. To remove the white, the blending mode for the layer was set to “multiply”. The entire layer was selected and copied. This allows only the black in its various transparencies to be copied. A new layer was added, filled with black and a mask added. The mask layer was isolated (option-click the mask layer) and the multiply layer was pasted (figure 39.). The original layer was deleted. The mask was then inverted (figure 40.) and the layer mask applied (figure 41.). The new layer can then be colorized with the hue and saturation panel.

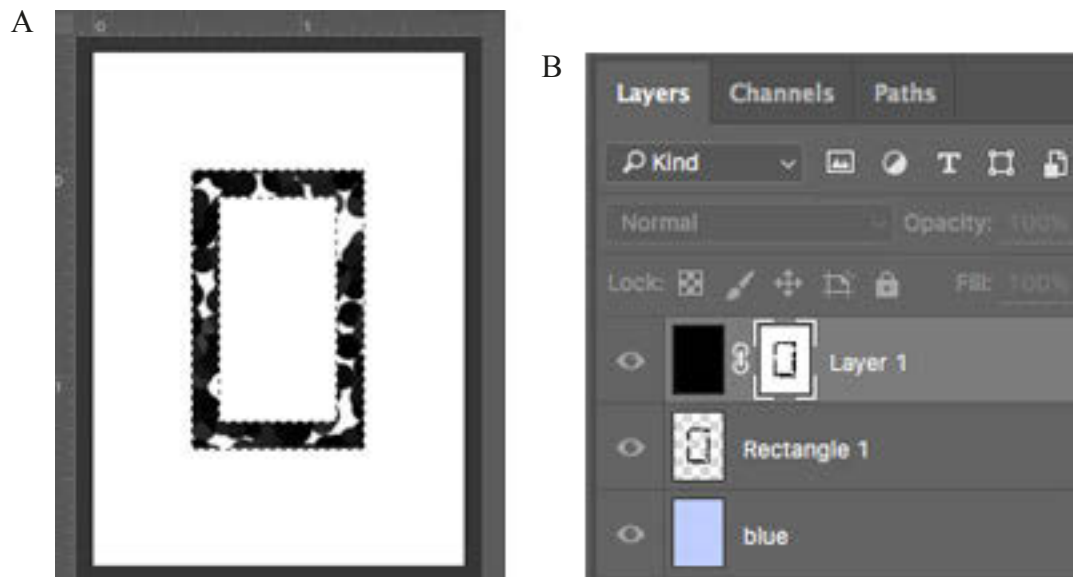


Figure 39. (A) The shape layer was set to the multiply blend mode and pasted in the mask layer applied to a new layer. (B) Layers are a black fill with a mask, the original shape layer with the multiplied blend mode, and a blue background layer.

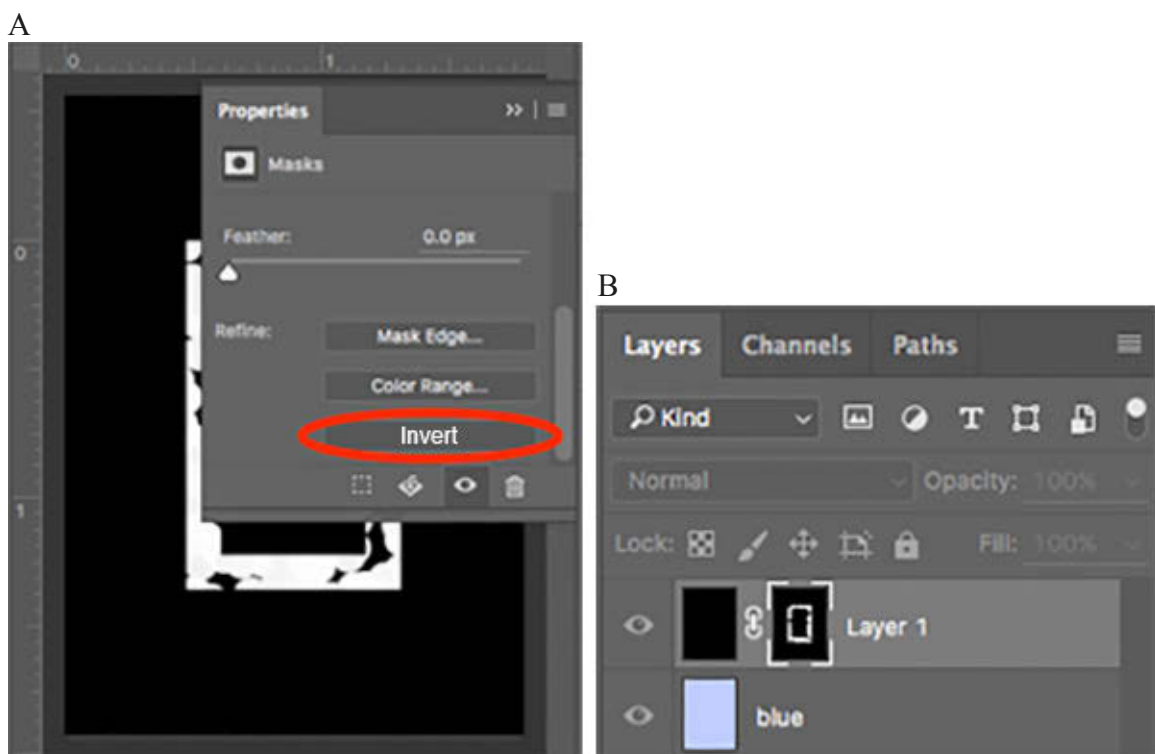


Figure 40. (A) The mask layer was inverted and the original shape layer deleted. (B) Layers are a black fill layer with an inverted mask and a blue background layer.

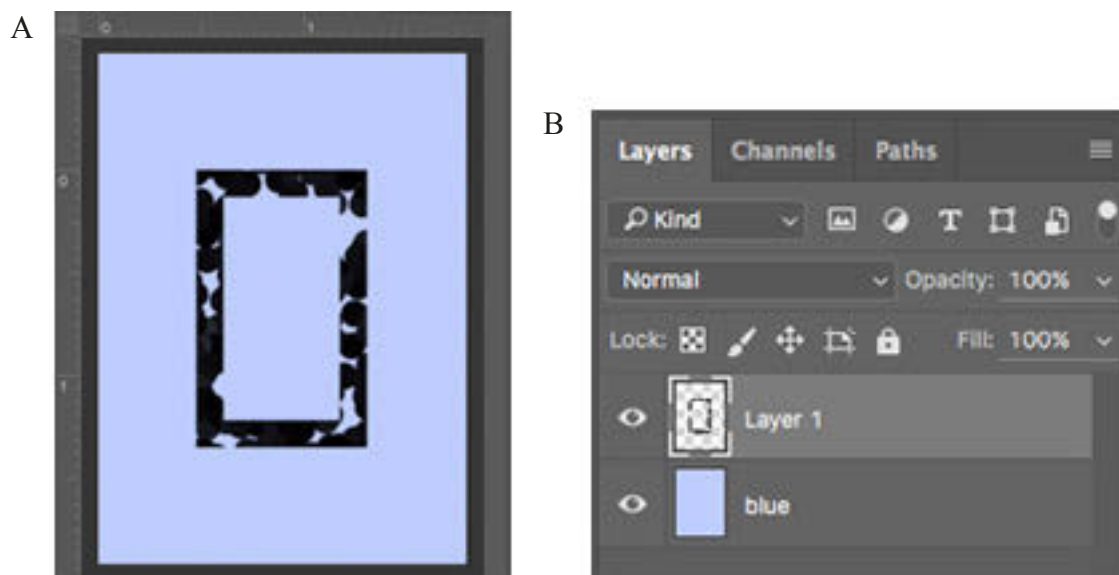


Figure 41. (A) The mask layer was merged with its base layer on blue background. (B) Layers are the merged mask layer on the blue background layer.

This style was developed for the art assets for several reasons. From a practical standpoint, two-dimensional artwork can be produced faster than three-dimensional assets. Because it may be viewed at a small scale (451x 254 pixels), a semi-graphic style was used. This reduces detail and creates broad simple shapes. However, the hand drawn look was brought back with the use of line variation and minor color shifts in the fill. Drop-shadows were later added in Adobe After effects CC 2015 to help define edges, create more visual interest by giving depth to flat images. This also creates a cut-paper effect. These elements of the human hand were selected to create a more personal effect than a purely graphical style.

For some assets, photographic references of the actual equipment were used. While certain assets such as the consent form were highly stylized for legibility others such as the specimen containers and autopsy lab were drawn fairly true to reality. This was done to keep the imagery honest to reality and address preconceptions. Assets were also designed to be reused throughout the remaining animations. Again, this creates a

more efficient workflow but it also reduces the cognitive load for the user.

Animation

An HD animation was completed in Adobe After Effects CC 2015. The size was set to a 16:9 ratio at 1280 x 720 pixels with the playback of 29.97 frames per second. A total of 143 layers were used to create the animation. The majority of the movement was key framed with the transform settings under each layer. Position, scale, opacity and rotation were the primary settings used to create the motion.

For the imported images a drop shadow was added with layers styles (layer > layer styles > drop shadow). This was done to give depth to the animation and help define the borders of the various assets making them easier to delineate on a smaller scale. The color of the drop shadow varied depending on the object below. A slightly darker color than the main color below was selected and the blend mode set to “multiply”. The opacity was reduced to varying degrees depending on the color. Distance and size also varied depending on the size of the asset relative to the stage. The angle was set to 120° (figure 42.). Trim paths was used for the animated dashed lines and signature (figure 43., figure 44.).

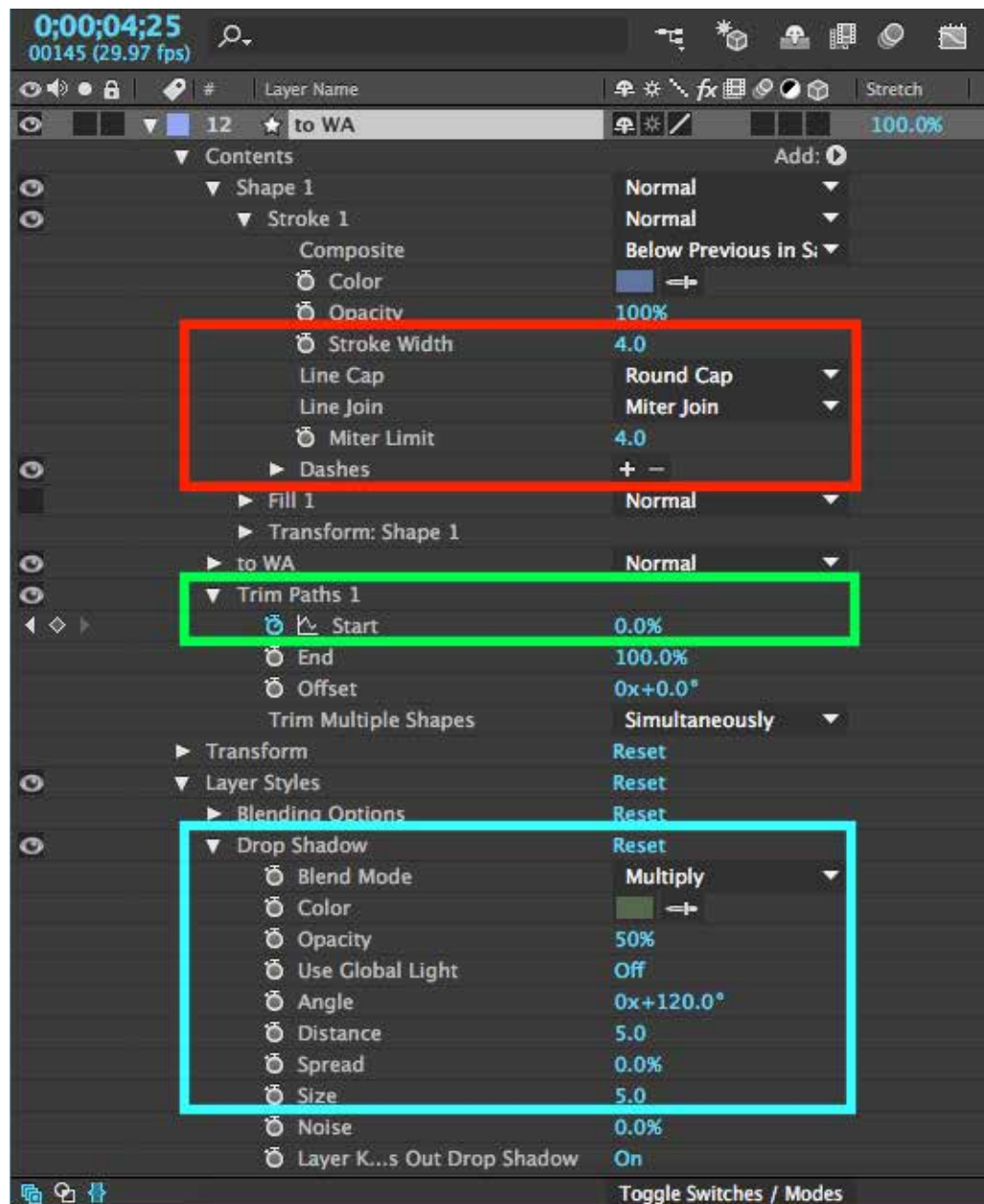


Figure 42. Drop shadow settings in Adobe After Effects CC 2015. Red rectangle indicates the location of the stroke settings, the green rectangle indicates the location of the trim path settings, and the blue rectangle indicates the location of the drop shadow settings.

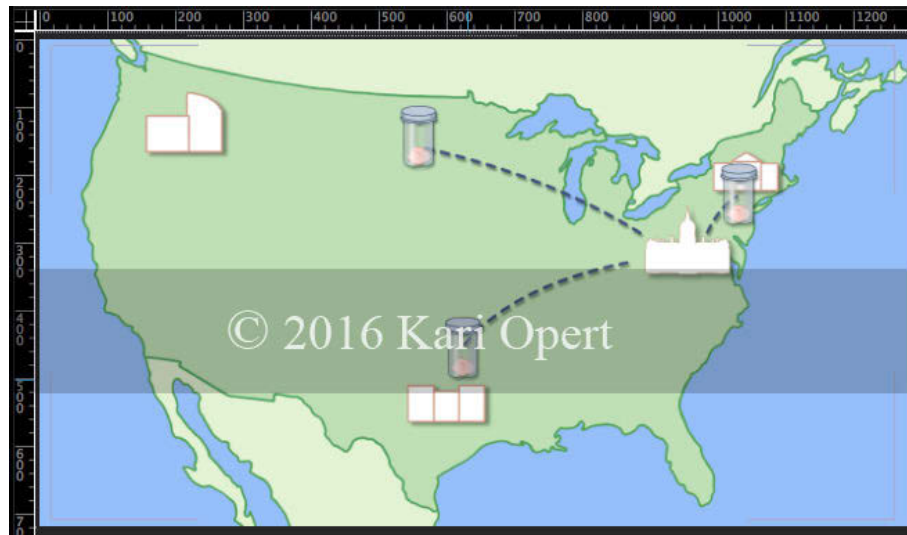


Figure 43. Still of the animation showing the dashed lines trailing the specimen bottles as they change position in Adobe Audition CC 2015.



Figure 44. Still of the animation showing the signature being drawn trailing the movements of the pen in Adobe Audition CC 2015.

The pen tool and convert vertex tool were used to create the paths. Under the settings for each line, the start setting located under trim paths 1 was used to animate the lines being drawn (figure 42). The dashed effect was created with the stroke settings by setting the

width to 4.0, the line cap to round cap, the line joint to miter joint, and the miter limit to 4.0 (figure 42.).

Multiple animated masks were used to produce the illusion of the cells being swabbed on the petri dish. Five art assets were imported and stacked (figure 45 A.). A mask was placed over each and the position key framed (figure 45. B). The swabs position was then key framed in sync the masks to create affect.

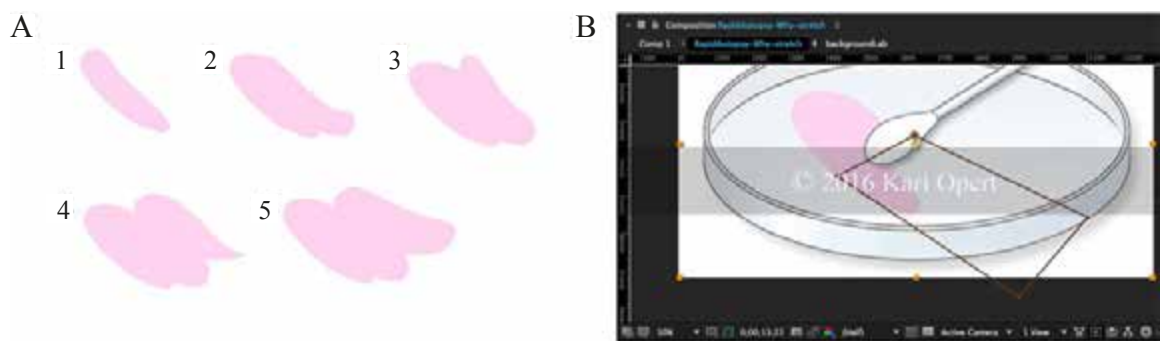


Figure 45. Animation of the cell swab. (A) the individual layers that compose the cells. (B) Still from the animation in Adobe After Effect CC 2015 showing the mask lines up with the cotton swab.

To help control the layers, and allow for greater ease adjusting some of the scenes, certain scenes were arranged in pre-compositions (figure 46). This was done by selecting a layer from the scene, control + click on it and selecting pre-compose from the menu (figure 47.)



Figure 46. Still of the animation showing risk concerns of sample collection during life was arranged in a pre-composition.

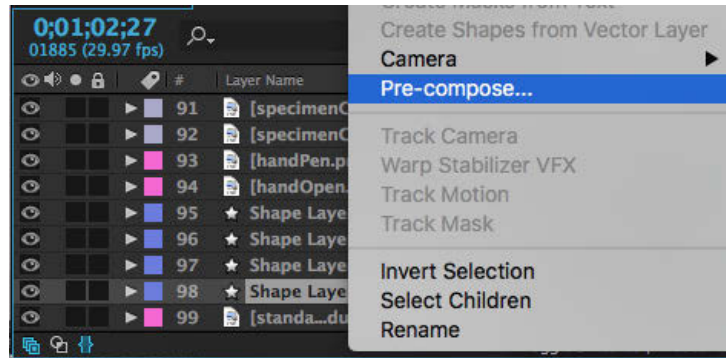


Figure 47. Creating a pre-composition in the Timeline window in Adobe After Effect CC 2015. .

After the assembly of the animation, it was decided to slow the pacing down. To stretch the whole composition all of the layers were selected and set in a pre composition. The animated layer was stretched to 110%. The audio layer was slowed in Adobe Audition CC 2015 then brought back into to the new composition. This was done to avoid the warping that occurs when audio is stretched in After Effects (figure 48.).

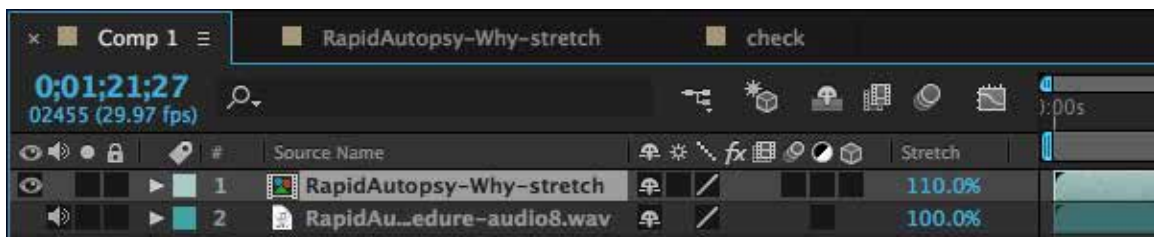


Figure 48. The Timeline window in Adobe After Effect CC 2015 after all the layers of the animation were set in a pre-composition. The audio file was stretched in Adobe Audition CC 2015 and re-imported to avoid warping.

The animation was rendered as a QuickTime video with video output set to H.264 compression format. The file was converted in Adobe Media Encoder CC 2015 with the H.264 HD 720p 29.97 preset to produce an mp4.

Evaluation

Stakeholder feedback about the animation's success as a patient education tool

was collected from individuals involved in the rapid autopsy program and from those who have patient contact through an online survey made available via Google docs and e-mail. Their responses informed changes to the pacing and audio for the reviewed animation. The following questions were asked.

1. The visual elements of the animation are...
 - Too vague
 - Appropriate
 - Too graphic

2. The amount of information provided is...
 - Too much
 - Appropriate
 - Too little

3. The pace of the animation is...
 - Too fast
 - Appropriate
 - Too slow

4. The tone of voice is appropriate for the topic.
strongly agree 1 2 3 4 5 strongly disagree

5. The information is provided in an appropriately sensitive manner.
strongly agree 1 2 3 4 5 strongly disagree

6. The animation aids the understanding of why JHU performs rapid autopsies.
- strongly agree 1 2 3 4 5 strongly disagree
7. The visual elements will aid understanding for those who have difficulty with reading and/or listening comprehension.
- strongly agree 1 2 3 4 5 strongly disagree
8. I would direct the patient/family to this resource.
- strongly agree 1 2 3 4 5 strongly disagree
9. Please provide additional comments below.

Post Evaluation Changes

Following the evaluation, the audio was re-recorded and the animation key frames adjusted to fit the new recording to slow the animation further. The recording was done with the same equipment and to the same specifications as the original. The editing required setting the amplitude to +4.5 dB, applying adaptive noise reduction, spot healing in the spectral display, and locking the stretch and pitch to 101.6% and -0.2 semitones with the audition algorithm. The new recording was two minutes and 27 seconds with 42 markers. The recording was brought into Adobe After Effects and the key frames of the animation were adjusted to match the new audio file resulting in a one minute and 49 second animation.

Results

Stakeholder Feedback

Evaluation of the animation by stakeholders lead to an increase in the length of the animation by approximately nine seconds to slow the pacing. Although it is possible to stretch the audio, the audio was also re-recorded with slower pacing to avoid warping and with improved enunciation.

Animation

A one minute and 49 second animation was created to explain why Johns Hopkins University performs rapid autopsies and to provide a brief introduction about the procedure. The beginning narration explains the desire to advance cancer research. This corresponds with an illustration of Johns Hopkins University's iconic dome (figure 49.).



Figure 49. Opening scene of Johns Hopkins University.

The foreground then slides down off screen and the background fades to a map of the Maryland region. The view then zooms out to encompass the 48 contiguous states while the building fades to a graphic representation of the general shape. This matches three other buildings on the map, including one in New England, one in the region of Texas and

one in the Region of Washington State. Three samples then appear over Johns Hopkins University and are distributed to the three other buildings each trailed by a dashed line (figure 50.).



Figure 50. Autopsy samples transferring to other research facilities.

One bar slides down and another up to divide the screen into three sections. Three researchers slide into the sections followed by the terms “prevention”, “diagnosis”, and “treatment”, each with a respective icon, fading on top (figure 51.).

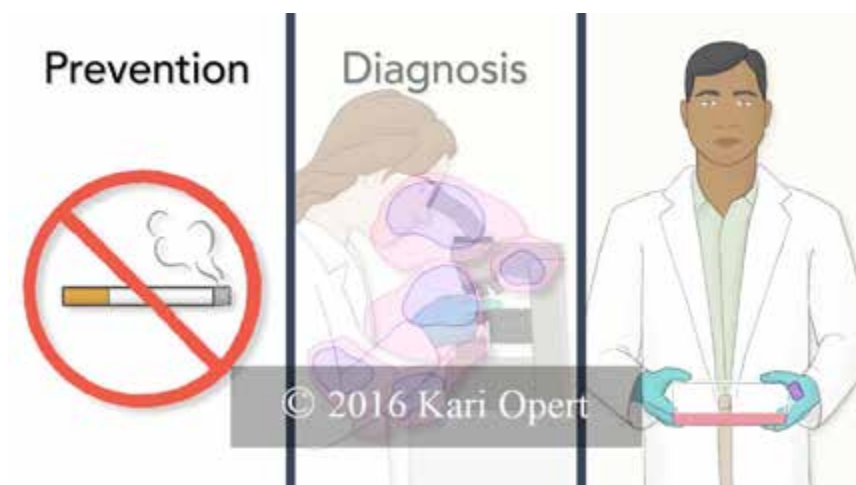


Figure 51. Areas of cancer research advancement overlapping researchers.

The narration then asserts the need for the procedure to take place shortly after death. With this, the imagery crossfades to the words “within 12 hours” followed by two rows of six hourglasses fading on (figure 52.). The next scene is a swab applying cells to a petri dish (Figure 53.). The view zooms in to see individual cells then to an individual fragment of DNA and RNA (Figure 54.).



Figure 52. The time frame in which the procedure must take place.



Figure 53. Cells being applied to a petri dish.



Figure 54. Swirling DNA and RNA fragments.

The narration continues with a description of the benefit of a complete autopsy as the scene crossfades to a figure with the organs that are examined during an autopsy (Figure 55.).

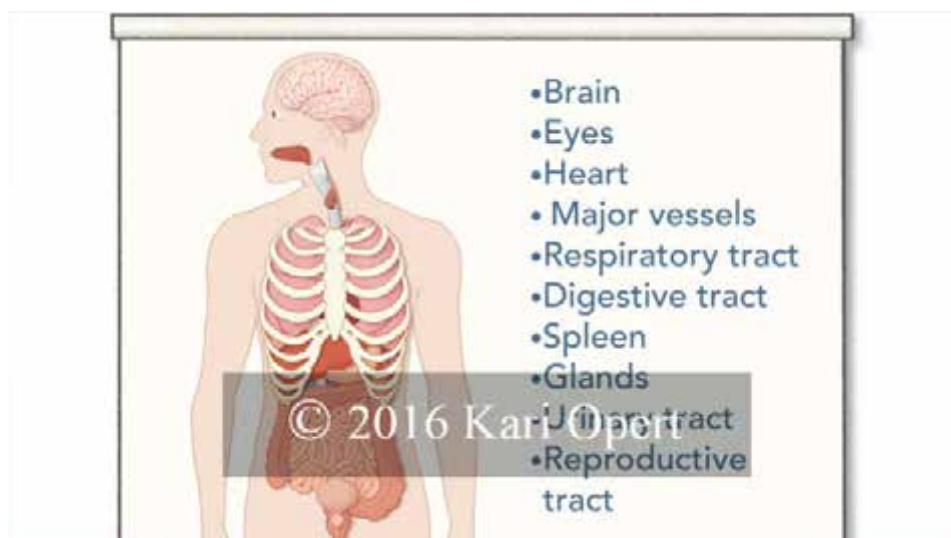


Figure 55. All of the organs involved in an autopsy examination.

The figure enlarges and shifts to the lower left of the screen followed by cancerous tumors sequentially appearing in the liver, lungs, and brain, as a flowchart identifying the organs appears simultaneously on the right (Figure 56.). This flowchart is replaced by the figure in black and gray, making the comparison of what is actually present and the limitations of what medical imaging can reveal (Figure 57.). This scene crossfades to a the outline of a figure in the center of the screen with the terms “benefits” and “risks” on either side to create the effect of a scale (figure 58.).

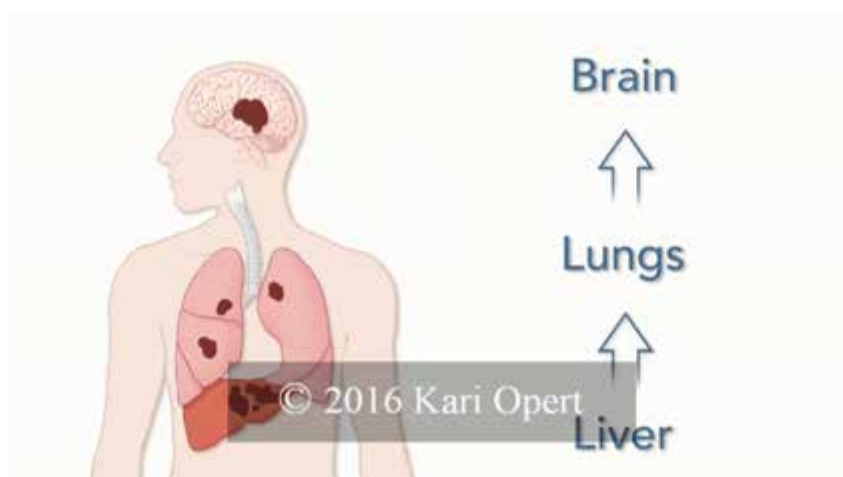


Figure 56. Map of the progression of disease.

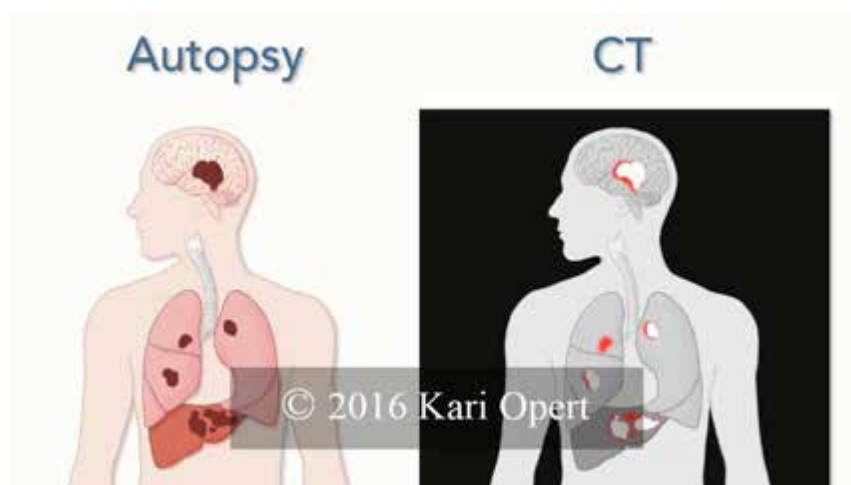


Figure 57. A comparison between what an autopsy may reveal about cancer versus medical imaging.

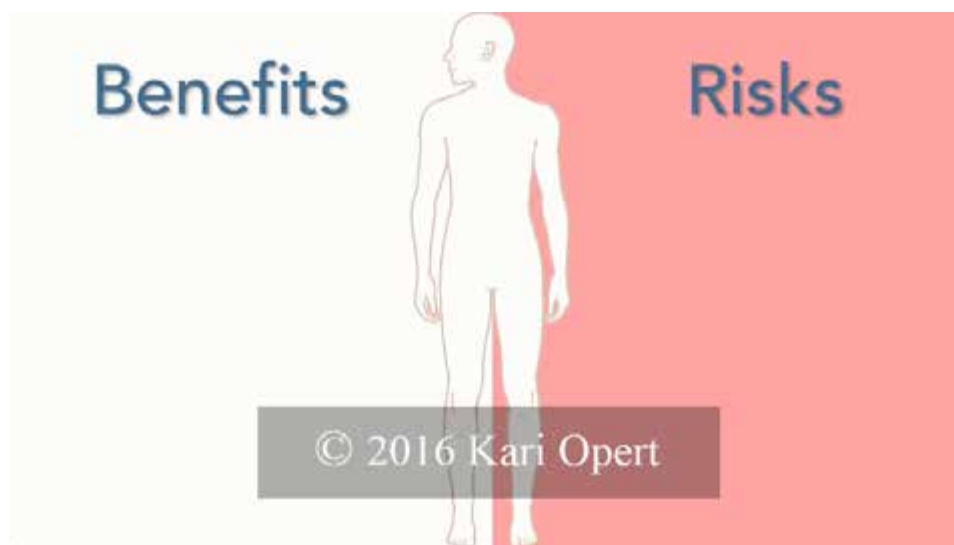


Figure 58. The benefits and risks scale.

This scale shifts left minimizing the benefits and highlighting the risks of invasive procedures during life to find out similar information that can be revealed during autopsy. The narration then shifts focus to what is involved in the procedure as the scene crossfades to the pathologist and team in the setting of the autopsy lab (figure 59.).



Figure 59. The pathologist and team that perform the rapid autopsy procedure.

This crossfades back to the figure and the individual organs examined are flashed on and off to help the viewer identify where each is located and provide a different view of the anatomy involved (figure 60.).

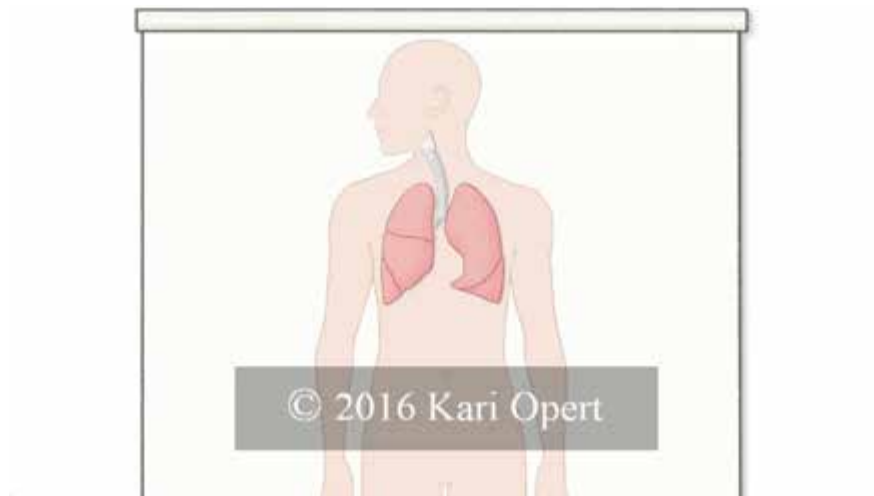


Figure 60. The organs involved in an autopsy examination cycling on and off one at a time.

The viewer is then introduced to the autopsy consent and the understanding that modifications can be made to the procedure (figure 61.).



Figure 61. The next of kin agreeing to the terms of the autopsy consent with no restrictions.

This scene crossfades to the three sample containers (figure 62.) to help understanding of what is meant by research samples and then crossfades back to the consent for the signature (figure 63.).



Figure 62. The autopsy samples.

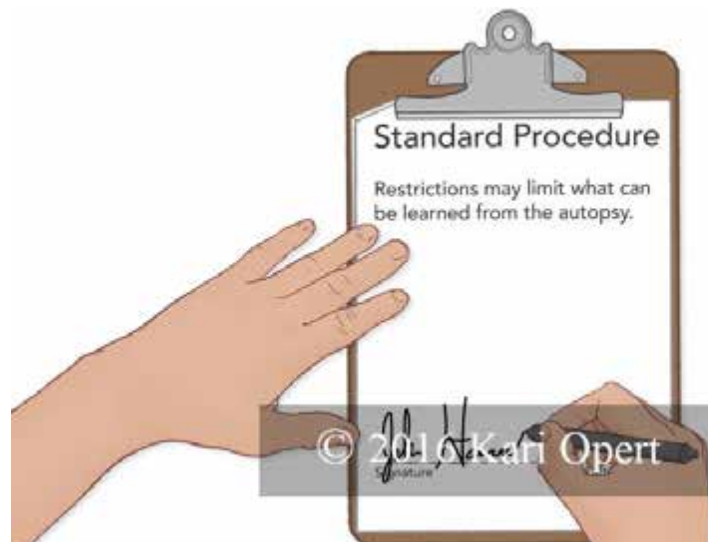


Figure 63. The next of kin signing the autopsy consent.

As one last reminder of the internal anatomy involved, the figure and organs again crossfade on (figure 64.), followed by the organs fading off and the incision lines fade on

to show that the full procedure can take place without affecting the bodies' presentation for a viewing (figure 65.).



Figure 64. Review of what organs are involved with a complete autopsy.

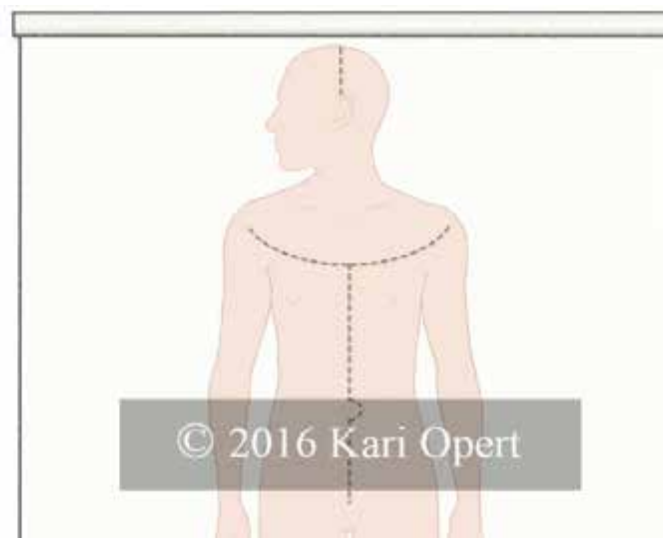


Figure 65. Identification of the incision locations to show that they will not prevent a viewing.

Interactive

A prototype of the interactive modules was created for the topic of rapid autopsy. When opened, the user is presented with nine buttons addressing eight topics related to rapid autopsy (figure 66.) and an option to display all of the text within the module (figure 67.). This was done because of the sensitive nature of the topic. This display allows the user to manage what topics he or she views providing control over what is learned.



Figure 66. Button options of the interactive module.

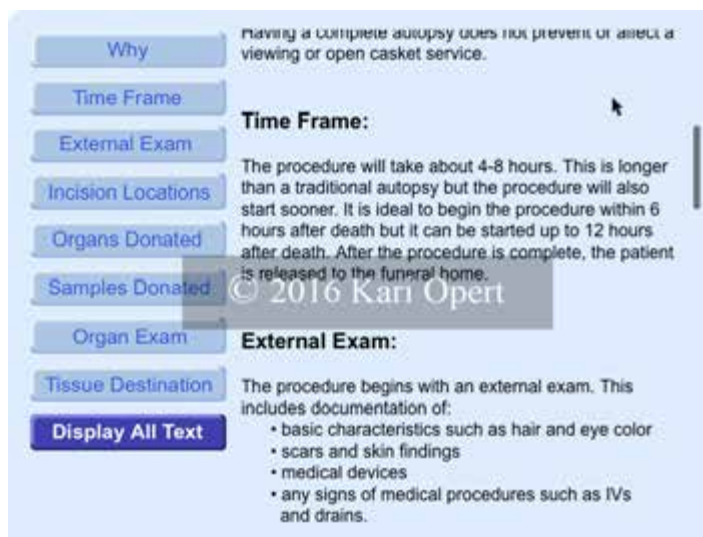


Figure 67. Scrolling through the text under the “Display All Text” option in the interactive module.

For the prototype, the content for “Why” and “Display All Text” is populated. The material available for “Why” is the model for the content of the remaining seven categories (figure 68.). This includes an animation and the script available in written format below. “Display All Text” provides all of the script for each of the categories.

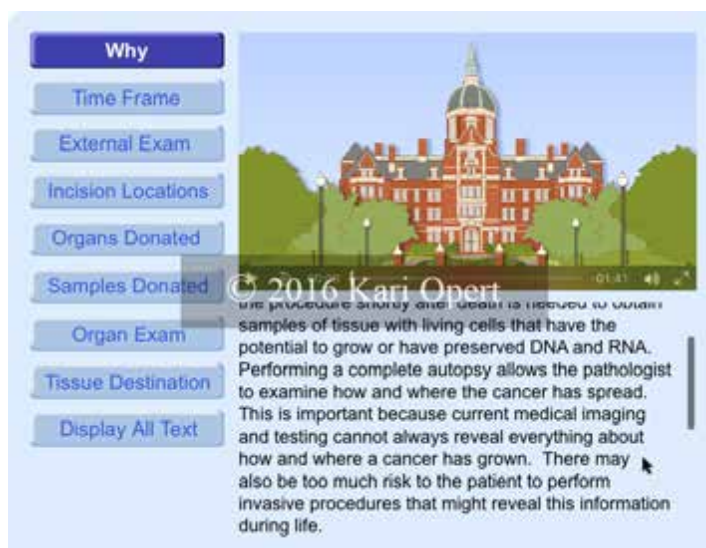


Figure 68. The animation and narration in text form for why rapid autopsies are performed.

Access to Assets

Assets can be viewed by contacting the author at kari.opert@gmail.com. The author may also be reached through the Department of Art as Applied to Medicine at <http://medicalart.johnshopkins.edu>.

Discussion

Addressing Autopsy Barriers

Several studies have revealed multiple barriers to autopsy and rapid autopsy for both families and physicians. For families, these include a lack of education, religious beliefs, psychological stress, and logistics (Alabran et al. 2013, McIntyre et al. 2013). Physicians cite a lack of knowledge of the procedure and its benefits and a reluctance to ask patients and families if they would want to consent to a standard autopsy or a research autopsy (Alabran et al. 2013, Spunt et al. 2012, McIntyre et al. 2013). These issues demonstrate the need for an educational tool.

Although only a prototype for this tool was created, the full script was written with these barriers in mind. A general lack of education was apparent for both groups, so it was important to provide a comprehensive overview about the autopsy and rapid autopsy. The first topic addresses cancer development and its relationship with genetics, that would be particularly helpful to the non-medical community. It provides a base knowledge of genetics that can be used to better understand how the rapid procedure benefits cancer research and the outcomes of the research. The next two topics cover what autopsy and rapid autopsy procedure involves. This includes explanations about why they are performed, the time the procedures will take, education about the steps of the full procedure and the anatomy involved, and the assurance that a full autopsy will not affect a viewing, and that modifications can be made to the procedure at the family's request. These last two points are reiterated several times throughout the script because the procedure can be adapted to comply with religious practices and to reduce stress the family may feel regarding the invasiveness of the procedure. The next topic specifically goes over the logistics involved in participating in the rapid autopsy program. It reviews the roles and requirements of the patient, family, medical staff, and Legacy Gift staff and addresses cost. Again, this is done to minimize stress, particularly after the patient has passed and to express the desire to keep the burden to the family and any intrusion

to the grieving process minimal. The benefits, research types, and research outcomes are addressed in the remaining sections. This information may be particularly beneficial for physicians' understanding of how rapid autopsy can contribute to medicine and the quality of patient care they can provide and may provide encouragement to ask patients and their families if they can explain the benefits of the procedure including those the patient or family may experience.

General healthcare complaints and health literacy were not ignored. Because the resource is meant for both a lay audience and medical professionals, it is written at a slightly higher level than would have been used for a lay audience. To compensate for this, in-line definitions of technical terms were included and the choice was made to break the information into smaller subgroups. This is also why the choice was made to present the information in the form of an animation since this has been shown to improve learning (van Weert et al. 2011, Houts et al. 2006).

With regard to empathy, the effort was made to anticipate concerns families might have that would affect their level of psychological stress or their grieving process. An example would be including the line "...we encourage families and loved ones to take all of the time they need with the patient after he or she has passed" when discussing the time frame in which the procedure must be performed after death.

Although, these barriers are addressed by the creation of and within the content of the educational tool, simply creating a resource does not fully address the lack of education barrier because it relies on either being directed to or found during a search for similar information. Those who come across the resource during their own inquiries are likely to already have some interest in learning about or participating in an autopsy or tissue donation research program. Those who are not active in learning about these topics remain difficult to reach. Also, this tool provides only a base of information and full learning will require more detailed inquiry that may be left to the responsibility of

patients, families and providers.

Benefit of a Web Based Resource

Providing the resource online is ideal for making the information widely accessible. Approximately 84% households have computers and approximately 74% use the internet (U.S. Department of Commerce 2014). This platform allows the opportunity for the information to be found without specific direction. This is desirable because one of the goals was to design an educational resource for a broad audience, including the lay and medical communities, about rapid autopsy but also about the benefits a routine autopsy can provide to medicine and patient care. For patients and families at Johns Hopkins who are specifically directed to the site, the material can be reviewed in the comfort of one's own home at any time. It allows a wide range of information to be made available without burdening the patient or family with take-home materials such as pamphlets or packets, which can be damaged or lost. Having the range of information is imperative, as the topics of most concern and value may vary from patient to family and depend on their background and the stage of disease.

Interactivity

One series of interactive modules was planned because of the cross over in the areas of education both patients and physicians are lacking. This also serves to reduce the scope of the project, which already requires the creation of seven interactive modules and 42 short animations to complete. This system would allow the modules to be posted to the site as they are completed.

An interactive also allows a collapsible format that presents the information in small sections, or larger sections, if desired, through the full text view. Given the sensitivity of the information, and the variability of what details different users will

want to know, this format was desirable to prevent an undue psychological stress and to help the user find pertinent information. This method allows the information to satisfy multiple learning theories including the cognitive load learning theory by reducing the amount of information the user is confronted with to increase learning. It also allows the information to be provided in multiple formats including text, narration, and visual reinforcements. This aligns with the dual coding learning theory, which asserts “Recall/recognition is enhanced by presenting information in both visual and verbal form” (Culatta 2015). It appeals to learning from verbal and non-verbal communication and allows the information to be comprehended with visual and auditory processing. Although breaking the information into sections requires more effort by the user to navigate, it is not likely that users, particularly patients and families will keep revisiting the site beyond the scope of their participation in the program.

Regarding the interactive development, deciding on how to create the scroll feature proved to be the most challenging aspect. Ultimately, simply applying the scroll to the overflow was selected, but only after testing other methods. An undesirable aspect of the automatic option is that the scroll bar only appears when the mouse is over the text. After web searches on how to develop this type of feature and experimenting with the code a working scroll bar was created. The drawback with this though, was it required the user to click and drag the handle of the scroll bar instead of being able to scroll with a touchpad. A parallax feature was considered to compensate for this; however, this would be an atypical solution that could interfere with intuitive use of the interface. User feedback for this feature is desirable.

Information Delivery

The animation is intentionally devoid of sound effects, music, and extraneous information to reduce interruption of the information being given. Including such details

may reduce the ability to maintain the line of thought and hinder overall learning (Mayer 2002, Houts 2006). The text is presented as a secondary element to the animation and narration. It is positioned below the animation and not in full view, meaning the user has to scroll through to read it all. Words are not highlighted to match the narration to reduce split attention. Although the presence of the text may add to the cognitive load, it appeals to other theories such as the theory of multiple intelligences, which challenges the notion that everyone can learn the same way (Culatta 2015). It encourages teaching in a way that appeals to multiple forms of intelligence, and the presentation of the information in the module appeals to linguistic, logical, spatial, and naturalistic intelligences. To reduce the cognitive load and allow the user to focus on the information, the interactive was designed with familiar elements such as buttons, having the cursor switch to the pointer over the buttons to indicate that they can be clicked, familiar video controls for the animation and a look that mimics the functionality of the website on which it will be hosted.

Software choices

The software used to create the prototype were: Adobe Illustrator CC 2015, Adobe Photoshop CC 2015, Adobe Edge Animate CC 2015, Adobe After Effects CC 2015, Adobe Audition CC 2015, Adobe Media Encoder CC 2015, and Axure Pro RP. Although there are similar products available, the range in the types of programs used varied significantly and Adobe products are specifically designed with compatibility in mind. Additionally, there is consistency within the interface design that makes use of a less familiar program more intuitive, which was crucial for developing the prototype within the allotted time frame. Axure was used to create a rough navigational prototype. Use of a program outside of Adobe for this did not complicate the process because it was not used to generate files to be integrated with any of the other programs and it has a fairly easy

interface for wire framing, although it is capable to develop more complex features.

Future Directions

The next steps would be to complete the recordings, art assets and animations for the remaining subtopics in the “Rapid Autopsy” module. For this thesis, only the animation was evaluated for its effectiveness as a patient education tool. This was due to the time constraints of the project. Although the prototype for the interactive was finalized, this was done while the animation was being reviewed. It was evaluated for patient education because the animation is meant to specifically aid learning for the lay population.

After the module is completed, it would be ideal to have an IRB approved protocol for evaluation of the module by health care workers and the patient population. The preferred healthcare provider audience would come from outside of Johns Hopkins University and not be familiar with the Rapid Autopsy program. Coordination with patient advocacy at Johns Hopkins could help to organize evaluation of the module by the patient population. For both groups it would be valuable to evaluate their knowledge of the topics addressed in the module before and after reviewing it as well as get opinions about the style, functionality, and their preferred learning method (animations or text). Revisions could be made to the existing module and this data would be used for the development of the remaining modules. Each module could be added to the Legacy Gift website as they are completed.

Conclusion

There is currently a dearth of information about autopsy directed to patients and families available online. Much of what is present is only presented in text format and leaves much about the procedure to the imagination. This thesis serves as the beginning steps for the development of a new strategy for communicating autopsy and rapid autopsy education. A strategy that those involved in patient care and the rapid autopsy program have expressed would benefit patients and families and is a resource they would share with patients and families.

There were two major challenges during the development of this online interactive resource. One was the broad audience including a lay and medical audience and the other the sensitivity of the topic. The first of these challenges was approached by designing for multiple learning theories and by presenting the information in multiple formats found to be effective for healthcare communication. The second challenge was addressed by designing to give the user control over what details they learn and by creating imagery that conveys information, such as elements of the procedure, in a non-graphic manner.

Efforts are being made to see the completion of the resource. As it is a new type of resource for communicating this information, it would benefit from further user testing. It is the hope of the author that this resource will serve to facilitate the conversation about autopsy and rapid autopsy between physicians and families, raise awareness of how these procedures can lead to improved patient care, and inspire additional autopsy education materials for patient education.

Appendices

Appendix A: Narrations

Cancer Development

DNA:

“Our bodies are made up of trillions of structures called cells. Nearly every individual cell contains the full set of instructions for how we are built and how we function. These instructions are called genes. These instructions are coded and inherited from our parents in the form of DNA (deoxyribonucleic acid). Our DNA contains separate strands. Each strand looks like a long twisted ladder. This structure is called a “double helix”. In DNA, the rungs of the ladder are made of paired structures called nucleotides. There are 4 types of nucleotides in DNA, “A” adenine, “T” thymine, “C” Cytosine, “G” guanine. “A” pairs with “T” and “C” pairs with “G”. Just as letters in the alphabet combine to form words, nucleotides form genes.”

Genes:

“A gene is a section of DNA that provides the code or instructions to create a specific protein. DNA will be transcribed into RNA (ribonucleic acid), which in turn will be translated into sequences of amino acids to create proteins. Proteins drive the function and organize the structure of our bodies. Humans have 20,000-25,000 genes.”

Chromosomes:

“DNA is twisted and coiled within the cell to form chromosomes. When a cell gets ready to divide, the chromosomes duplicate themselves so that each new daughter cell will have a full set of chromosomes. Cell division is called mitosis.”

“A normal human has 46 chromosomes. One set of 23 originally comes from the mother’s egg cell and a second set of 23 comes from the father’s sperm cell. In females, the 23 chromosomes from each parent form matching pairs. In males, 22 of the

chromosomes are paired but the two sex chromosomes are unpaired. Males have an “X” and a “Y” chromosome and females have two “X” chromosomes. When the egg and the sperm cell come together, they combine paired genes from each parent which may have variations in their nucleotide base sequence which will create predispositions towards certain characteristics such as blue eyes versus brown eyes.”

“Genes contain all of our code for how we are built and function. Any damage to our DNA or chromosomes is damage to our genes which can affect our health. Our bodies can fix some DNA damage and some damage may not have any noticeable effect. However, some damage can result in diseases and sometimes death.”

Cell Growth and Replication:

“The cell cycle is a complicated process during which a cell grows, copies its DNA and splits to create two daughter cells. This process is known as cell proliferation. The cell cycle has 3 stages, interphase, mitosis, and cytokinesis. Interphase is broken down into three phases. First is Gap 1 when the cell grows to size, second is S-phase when the DNA is copied, and third is Gap 2 when the cell finishes growing and structures called centrosomes form. The next stage in the cell cycle is mitosis which has five phases. First, is prophase, when DNA coils into the chromosome structure, structures called microtubules extend from centrosomes and the nucleolus disappears. Second, is prometaphase when the nuclear membrane breaks down and the microtubules extend to chromosomes. Third is metaphase when the chromosomes align along center of cell. Forth is anaphase when the sister chromatids separate and migrate to poles of cell. And fifth is telophase when the microtubules separate, new nuclear membranes form and the chromosomes lose shape. The last stage in the cell cycle is cytokinesis when the cytoplasm splits forming 2 separate cells.”

DNA Replication:

“During DNA replication, the DNA helix is first split by the protein helicase. Next, other proteins come to help stabilize the unwound structure. Lastly, the protein DNA polymerase adds nucleotide bases to create new strands on the separated edges. One strand has nucleotides added continuously and the other in sections, which have to be marked and fused.”

Gene Mutation:

“A gene mutation is a change in the DNA nucleotide sequence. Some have little to no effect while others can lead to severe disease or even death. It typically takes several kinds of mutations to occur for cancer to develop. For example the ras protein signals for cell replication. A mutation in the ras gene can lead to the creation of faulty ras proteins that are not able to shut off and continually signal to the cell to replicate. This can cause too many cells to proliferate and grow in abnormal ways and locations.”

“Inherited mutations are gene mutations that are present in the genes of the egg or the sperm. These mutations will be present in all cells or “germline” of the developing organism. Some inherited mutations can make it more likely that other mutations will occur, therefore increasing the risk for cancer to develop. “

“Acquired mutations occur from errors when DNA is being copied during cell replication. They may also occur from environmental exposures that may harm DNA and it may not be repaired properly. This type of mutation can lead to incorrect pairs of nucleotides, extra sequences of gene code being added or needed sequences being deleted. Most cancers develop from acquired mutations. This is why cancer often develops later in life after mutations have compounded and/or after prolonged exposure to a carcinogen or cancer-causing agent. “

“We do not fully understand yet how all cancers develop and not all show a clear mutation or known cause.”

Metastasis:

“Metastasis is when cancer spreads from where it started to other parts of the body. Cancer cells can travel in the body through the bloodstream or lymphatic system (vascular system that carries and produces lymph fluid and immune cells) to different locations and begin to grow. Certain cancers tend to spread to particular locations. This knowledge can help the oncologist determine where a cancer started if it has already metastasized and where to look for other tumors. Aggressive spread and/or ability to metastasize is what makes a tumor malignant. Benign tumors do not generally have this ability. Metastatic cancers may also be genetically different from the primary tumor. This means that not all of the cancer may respond the same way to a treatment. Some of the tumors may get smaller or disappear with treatment while others continue to grow.”

Traditional Autopsy Procedure

Why:

“The reasons for a traditional autopsy are to:

- Determine the cause of death.
- Determine efficacy of treatment and/or if the diagnosis was appropriate.
- Examine the progression of a disease to learn more about it.
- Answer questions that the family has about the disease or what happened with the patient.
- Educate medical students, residents, and other physicians.”

“The autopsy is done by a team led by a medical doctor called a Pathologist. A complete autopsy includes examination of all organs including the brain, and at some institutions, the eyes as well. Modifications can always be made to the procedure at the family’s request. For example the family can request a chest exam only or restrictions to other areas of the body. However, this may limit what can be learned from the autopsy. Having a complete autopsy does not prevent or affect a viewing or open casket service.”

Consent:

“A patient cannot consent to his or her own autopsy in the state of Maryland. Autopsy consent can only be signed by the legal next of kin after the patient passes. Medical power of attorney does not continue after death. The order of who may sign is determined by state law. The order is the spouse (even if separated, but not if divorced), if there is no spouse then adult children, then parents, siblings, and so on.”

Time Frame:

“The procedure is usually completed in approximately 3 hours. At Johns Hopkins University, autopsies are performed 7 days per week between 8:30 AM and 3:30 PM, then the patient is released to the funeral home.”

External Observations:

“The procedure begins with the documentation of:

- basic characteristics such as hair and eye color,
- scars and skin findings,
- medical instrumentation, and
- any signs of medical procedures such as IVs and drains.”

Incision Locations:

“A full autopsy requires a:

- U-shaped or Y-shaped incision: from shoulders to sternum to pubic bone (around navel) to access the organs and major vessels and an
- Ear-to-ear incision: over the crown of the head to access the skull and brain.
- No incisions are needed for the eyes.”

Organs Removed:

“The chest plate (ribs) is set aside to access the

- heart and major vessels, the
- respiratory tract including the trachea and lungs, the
- digestive tract including the tongue, esophagus, stomach, intestines, liver, gallbladder, and pancreas, the
- urinary tract including the kidneys, ureters, and bladder, the
- thyroid, parathyroid, and adrenal glands, the
- spleen, and the
- reproductive tract.”

“In a complete autopsy the organs are removed all at once “en bloc” and examined. The top of the skull is set aside to access the brain. No incisions are needed to remove the eyes. Additional samples such as blood may be taken.”

Organ Examination:

“The organs are examined visually and any abnormal findings such as changes in color or markings are recorded. The weight of organs is measured and recorded. Organs such as the gallbladder are opened to examine contents and check the internal surface for abnormalities. Solid organs such as the liver are sectioned for examination. Samples of organs are taken to be made into microscopic slides for evaluation. Findings are photographed.”

Destination:

“The chest plate and top of the skull are returned. Organs will typically be preserved in fixative and kept until the autopsy report is finalized, after which they will be incinerated. The family can request that organs be returned at the time of the autopsy. When the autopsy procedure is complete, the funeral service is contacted to transport the patient and prepare the body for the memorial service. A complete autopsy including brain and eyes will not restrict a viewing at a funeral service.”

JHU Rapid Autopsy Procedure

Why:

“Johns Hopkins University performs rapid autopsies to advance cancer research in the areas of prevention, diagnosis and treatment. Performing the procedure shortly after death is needed to obtain samples of tissue with living cells that have the potential to grow or have preserved DNA and RNA. Performing a complete autopsy allows the pathologist to examine how and where the cancer has spread. This is important because current medical imaging and testing cannot always reveal everything about how and where a cancer has grown. There may also be too much risk to the patient to perform invasive procedures that might reveal this information during life.”

“The procedure is done by a team led by a medical doctor called a Pathologist. A complete autopsy includes examination of all organs including the brain, and at some institutions, the eyes as well. Modifications can always be made to the procedure at the family’s request. For example, the family can request a chest exam only or restrictions to other areas of the body, or may request that only samples for research are removed. However, this may limit what can be learned from the autopsy. Having a complete autopsy does not prevent or affect a viewing or open casket service.”

Time Frame:

“The procedure will take about 4-8 hours. This is longer than a traditional autopsy but the procedure will also start sooner. It is ideal to begin the procedure within 6 hours after death but it can be started up to 12 hours after death. After the procedure is complete, the patient is released to the funeral home.”

External Exam:

“The procedure begins with an external exam. This includes documentation of:

- basic characteristics such as hair and eye color,
- scars and skin findings,
- medical devices, and
- any signs of medical procedures such as IVs and drains.”

Incision Locations:

“Sterile procedure is used for the incisions and sample collection. This means that the gloves and instruments such the scalpel and sample containers are sterile and the skin is cleaned with iodine at the incisions. A full autopsy requires a:

- U-shaped or Y-shaped incision: from shoulders to sternum to pubic bone

(around navel) to access the organs and major vessels and an

- Ear-to-ear incision: over the crown of the head to access the skull and brain.
- If tumor is present in other locations, samples may be taken. No areas which would be visible during a viewing such as the head, arms and hands, will be sampled without special permission from the family.”

Organs Donated:

“The chest plate (ribs) is set aside to access the

- heart and major vessels, the
- respiratory tract including the trachea and lungs, the
- digestive tract including the tongue, esophagus, stomach, intestines, liver, gallbladder, and pancreas, the
- urinary tract including the kidneys, ureters, and bladder, the
- thyroid, parathyroid, and adrenal glands, the
- spleen, and the
- reproductive tract.”

“Organs may then be removed all at once “en bloc” or may be removed in separate sections depending on the case, or may not be removed if that is the family’s preference. The top of the skull is set aside to access the brain. No incisions are needed to access the eyes. At the end of the procedure, the chest plate and top of the skull are returned.”

Samples Donated:

“Samples are collected from:

- Cancer tissue from different locations of primary and metastatic tumors. This is important because tumors may have genetic differences that can inform why a treatment did or did not work and help the search for new treatments.
- Normal tissue samples. This is important for comparison to tumor tissue, to find the changes that make cancer, cancer. Some researchers also need normal tissues for other types of non-cancer research.
- Fluids including blood, for immune cells and blood counts, fluids in body cavities, and spinal fluid.”

Organ Exam:

“The organs are examined visually and any abnormal findings such as changes in color or markings are recorded. The weight of organs is measured and recorded. Organs such as the gallbladder are opened to examine contents and check the internal surface for abnormalities. Solid organs such as the liver are sectioned for examination. Samples of organs are taken to be made into microscopic slides for evaluation. Findings are photographed.”

Tissue Destination:

“Fresh, frozen, and preserved samples are taken at most rapid research autopsies for use in different types of research. If the family permits, samples can be taken for different researchers, including those seeking normal as well as tumor tissue. With permission, samples can also be sent to researchers at different institutions. The patient and family can decide at the time of study consent what types of studies may be done and

where the tissue may be sent.”

“Organs will typically be preserved in fixative and kept until the autopsy report is finalized, after which they will be incinerated. The family can request that organs be returned at the time of the autopsy.”

“When the autopsy procedure is complete, the funeral service is contacted to transport the patient and prepare the body for the memorial service. A complete autopsy including brain and eyes will not restrict a viewing at a funeral service.”

Participation Process

Discussion/ Research Consent:

“The process will typically begin with a discussion between the patient and family and the treating doctor, often an oncologist. At this time the reason for the research and participation process is explained. If the patient and family decide to participate in the Legacy Gift program the patient will sign a consent form to say they agree to participate in the study. There is no cost to the family for participation.”

“It is important to know that a consent for the autopsy itself is different from the study consent. The autopsy consent must be signed by the legal next of kin only after the patient passes away.”

“A patient cannot consent to his or her own autopsy in the state of Maryland. Medical power of attorney does not continue after death. Autopsy consent can only be signed by the legal next of kin after the patient passes. The order of who may sign is determined by state law. The order is the spouse (even if separated, but not if divorced), if there is no spouse then adult children, then parents, siblings, and so on.”

“A representative of Legacy Gift will then contact the patient and family to

discuss any particular wishes regarding the autopsy and set up logistics of transportation if the patient will be at home or in hospice care when the time comes.”

Transportation Arrangements:

“JHU will organize the transportation arrangements with a transportation service or if preferred, the funeral home of the family’s choice. When the transportation service is used for the transit to Hopkins, the family’s funeral home will still pick the patient up from Hopkins after the procedure. The family will not be charged for the transportation to Johns Hopkins.”

After Death:

“Immediately when the patient has passed, a hospice representative or family member pages the Legacy representative. This is at any time, day or night. The legal next of kin will then fill out and sign the autopsy consent form with a witness signature and either email or fax it to the Pathologist for approval. If no email or fax is available a telegram service may be used.”

“When the consent has been cleared, the Legacy representative will activate the transportation process. The rapid autopsy cannot take place without both a study consent filled out before the patient passes and an autopsy consent filled out after the patient passes.”

“Though ideally the autopsy will be performed within 6 to 12 hours of the death, we encourage families and loved ones to take all of the time they need with the patient after s/he has passed.”

Autopsy and After:

“The autopsy procedure usually takes about 4-8 hours. After it is complete, JHU will contact the funeral home to transport the body to be prepared for the memorial

service. Having a full autopsy does not prevent a viewing at a memorial service.”

Rapid Autopsy Benefits

Large Late-stage Samples:

“Although diagnostic biopsy samples and tumor resections may produce some testable tissue, samples tend to be very small or only at specific stages of disease. This procedure allows researchers to examine the cancer at its terminal stage when treatment may no longer be effective. Ample tissue samples means tissue is available for testing by more researchers and for a greater variety of research. This is especially important for rare cancers.”

Multi-region Samples:

“A rapid autopsy allows for the collection of multiple samples from the same tumor and samples from metastatic tumors that have spread to different locations. These tumors may be genetically different from the first tumor and from each other. Researchers can also investigate how a tumor has evolved to become resistant to treatment.”

Tissue Cultures:

“Performing the autopsy soon (within 6 hours) after death means there is a greater likelihood that the cells from tissue samples can be cultured or grown in the lab or used to create animal models of the disease. These cultures allow researches to look for cancer causes, test new treatments and look for methods of prevention.”

Compare to Non-cancer Tissue:

“During the autopsy, samples of nearby more normal tissue can also be taken for comparison to the tumor tissue. This is important for helping research investigate what went wrong in the cancerous tissue. Understanding why and how the tissue became unhealthy allows researchers to look for new treatments and preventative measures to

reduce the chances of the cancer developing in the first place.”

Bio Repository:

“A bio repository is a place where samples can be stored for future research. This is an important resource for the development of future studies. Having specimens available also enables greater opportunities for research on rare cancers. As well as contributing to researchers, Legacy Gift autopsy samples are also banked for future investigation (where permitted by the study consent).”

Cancer Spread Patterns:

“A complete autopsy allows the pathologists to look for additional areas of previously unknown metastasis that were not visible on imaging. This can broaden the knowledge of where specific cancers tend to spread and how much cancerous tissue is actually present in the patient, as well as the reasons why patients die from their cancer.”

Family and Patient Contribution:

“Participation in the program can provide families and patients some solace by knowing that they are helping others including those battling the same type of cancer. This amazing contribution is what we call the “Legacy Gift”. An autopsy may help explain how the cancer led to the patient’s death and an understanding of the full extent of the cancer. It may reassure that nothing else could have been done for the patient. In some cases the procedure also contributes to the cosmetic result at a funeral.”

Research Types

Cell Culture:

“For a cell culture, tissue samples are removed and placed in a container with special growth medium to keep them alive. They are specially processed and may be taken from an initial culture and placed in a new container to continue the growth of the

cells. This next stage of growth is the establishment of a cell line.”

“This is significant because researchers can grow continually replicating cell lines. This is ideal for repeating experiments, as the cells with the greatest propensity for replicating will take over creating a genetically uniform cell culture. It provides a simple cell model that can be used for chemotherapy drug testing.”

Xenografts:

“A xenograft is the creation of an animal disease model. Viable tumor tissue or tumor tissue with the potential to grow is obtained from the patient and transplanted into an animal such as a mouse. The donated tissue sample is cut into very small portions or broken down into individual cells. The tumor tissue is then placed into the mouse. It may be placed in the same site as that the tumor originated from or may be placed in an unrelated region such as under the skin. When the tumor grows, it can be examined, genetically sequenced, and therapies can be tested on it. “

“A xenograft allows the growth of tumor that is genetically and environmentally similar to the tumor in the patient. These models can be a better predictor of how well therapies would work in the patient than cell lines.”

DNA Sequencing:

“DNA sequencing means determining the order of the nucleotide base pairs in a strand of DNA. Because DNA can be divided into regions called genes, when researchers sequence DNA they learn the sequence of individual genes.”

“Researchers can then look for the mutations by comparing the cancer sequence to the sequence of normal tissue. They can look for similarities and differences between cancer types, between the same cancer type in different patients, and between the tumors in a single individual. Cancers are frequently heterogeneous, meaning they are genetically

different in different locations. Understanding how a cancer has evolved genetically in each person allows for personalized targeted treatment. A drug to treat one type of cancer may work for another type if they have a similar genetic mutation.”

RNA Sequencing:

“Ribonucleic Acid or RNA sequencing means determining the order of the nucleotide bases in a strand of RNA. The nucleotides are adenine, uracil, cytosine, and guanine. RNA is needed to “express” a gene or create the gene product. RNA is transcribed from DNA. During transcription, it may undergo changes called “alternative splicing”. It may also undergo changes after being transcribed. After the RNA is transcribed from the DNA, the RNA code is translated to create many different proteins in a process called “translation”.”

“RNA sequencing will show mutations that occur during RNA transcription directly from DNA including errors in splicing. It also identifies errors in translation, shows what proteins are being created, and the amount of protein.”

Protein Studies:

“Proteins are large molecules made of amino acids. They are built by RNA and ribosomes in cells according to DNA coding in a process called translation. Proteins vary in size and shape to support their function. They are worker molecules in the body playing roles in everything from cell function and growth to tissue structure.”

“Proteomics is the study of the structure and functions of all proteins. Proteins are studied by: 1. Mass Spectrometry- molecule is added, made + (or-), broken into parts, accelerated, force is added and will deflect the different size particles differently so that they may be detected. 2. Protein microarrays- Proteins are bound to a bead or plate. Probes with fluorescent markers are then added and reactions between the proteins and

probes can be detected using a scanner which indicates what types of proteins are present and how much.”

“Genes are like a recipe; they tell you what can be made. Proteomics looks at what is actually made, the product of the recipe. Proteins can undergo additional changes after translation that can alter their shape and function. This means a single gene can encode many proteins. If we understand the normal for each protein, we can identify the abnormal, which can indicate a disease or condition. The presence or absence of abnormal proteins can help determine if a person has cancer and if treatment is working. They act as a “bio-marker”- a substance that can be measured or evaluated that indicates the presence of a disease or condition. Blood taken at autopsy could be used to help identify biomarkers that might improve early detection of cancer.”

Immune Studies:

“Antigens are proteins on cells that can help identify cells. Antibodies are proteins that will bind to particular antigens. An antibody can be bound (or “conjugated”) to an indicator such as a colored staining marker. After binding and washing steps, the colored marker will show on a microscopic slide if the antigen is present.”

“Antibodies can be used to identify proteins indicative of the presence and type of cancer for diagnosis. This type of research provides the opportunity to look for additional biomarkers.”

Rapid Autopsy Research Outcomes

What We are Looking For:

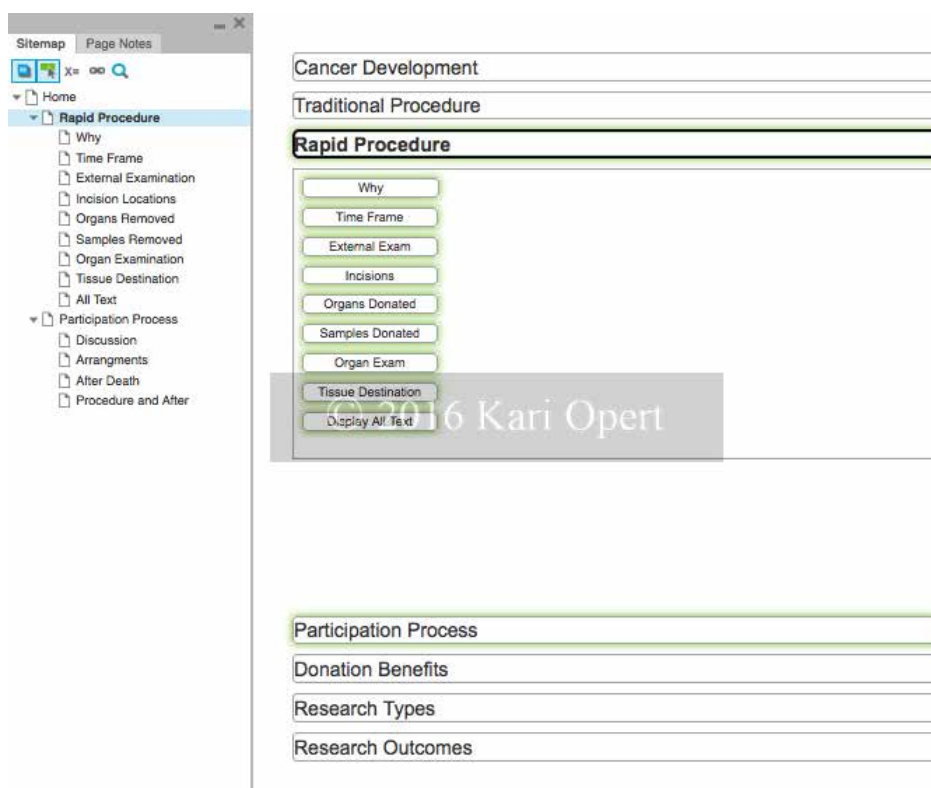
“Cancer can develop when DNA, RNA, and/or proteins are abnormal or damaged. Most often more than one gene error will be involved in causing cancer and different types of cancer have different mutations. Multiple areas of cancer spread in the same

person may even have different mutations. Researchers are working to develop treatments that are personalized to a patient's particular cancer to better the odds of fully curing it. They are looking for biomarkers, or measurable cancer indicators, to detect cancers earlier. And they are looking at how the mutations occur to identify risk factors. Studies from the Johns Hopkins University rapid autopsy program have involved many cancers such as melanoma, sarcomas (connective tissue tumors), prostate, ovarian, kidney, and breast cancer, and pediatric brain cancers and will continue to expand to include other types."

What We are Learning:

"Researchers have learned more about how certain cancers spread and what makes them deadly, for example, whether they are aggressive locally or spread throughout the body. They are exploring how cancer evolves by looking at the genetic changes at different tumor sites. They are evaluating the action of the body's own immune system on cancer and how to boost its effects. They are searching for biomarkers that can diagnose cancer earlier and detect which cancers will spread and have a bad outcome. They are testing new therapies on cancer cells and finding mutations in common across cancers that suggest new treatments."

Appendix B: Axure Pages



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Incision Locations

Organs Removed

Samples Removed

Organ Examination

Tissue Destination

All Text

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After Death

Procedure and After

Cancer Development

Traditional Procedure

Rapid Procedure

Why

Time Frame

External Exam

Incisions

Organs Donated

Samples Donated

Organ Exam

Tissue Destination

Display All Text



JHU performs rapid autopsies to advance cancer research in areas of cancer prevention, diagnosis and treatment. Completing the autopsy shortly after death is necessary to obtain samples of tissue that have the potential to grow. Completing a full autopsy allows the pathologist to examine how the cancer has progressed. This is important because current medical imaging and testing cannot reveal everything about how and where a cancer has grown and the risk of performing additional procedures that may reveal this information to the patient does not outweigh the benefit. The autopsy is completed by a medical doctor called a Pathologist. Will not change the quality of care or reduce cost of care, ownership of specimens, will not benefit or profit from the research.

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Cancer Development

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Rapid Procedure

Why

Time Frame

External Exam

Incisions

Organs Donated

Samples Donated

Organ Exam

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Display All Text



The procedure takes slightly longer than the traditional procedure. It is completed in about 4-6 hours. It also starts sooner 6-12 hours after death (<6 ideal)

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Traditional Procedure

Rapid Procedure

Why

Time Frame

External Exam

Incisions

Organs Donated

Samples Donated

Organ Exam

Tissue Destination

Display All Text

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This part of the procedure includes observation and documentation of any marks on the body. This may be things like swelling and bruises.

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Traditional Procedure

Rapid Procedure

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Time Frame

External Exam

Incisions

Organs Donated

Samples Donated

Organ Exam

Tissue Destination

Display All Text

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Sterile procedure (skin sterilized at incisions; sterile scalpel used) 1. Y-shaped: from shoulders to bottom of sternum to pubic bone (around naval) 2. U-shaped: from shoulders across mid sternum to pubic bone (around naval) 3. Ear-to-ear: over the crown of the head to access the brain. No incision needed for the eyes. These incisions are required for a complete autopsy. The patient and family will discuss the procedure and decide whether they want a full or partial autopsy. If partial, the patient and family will decide what parts of the procedure will and will not be completed. Having a full autopsy does not prevent having an open casket memorial service.

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Cancer Development

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Samples Donated

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The chest plate is removed to access the heart, major vessels, tong, esophagus, stomach, intestines, kidneys, reproductive tract, trachea, lungs. The top of the skull is removed to access the brain. No incisions are needed to remove the eyes. Organs may be removed all at once "block" or may be removed in separate sections depending on the case. This is what is required for a full autopsy. The patient and family will discuss the procedure (with oncologists?) and decide whether they want a full or partial autopsy. The patient/family can request modifications to the procedure such as what organs are removed, if the organs are to be returned to the body, and what tissues are sampled.

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Cancer Development

Traditional Procedure

Rapid Procedure

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External Exam

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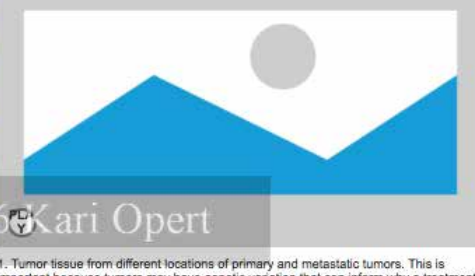
Organs Donated

Samples Donated

Organ Exam

Tissue Destination

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1. Tumor tissue from different locations of primary and metastatic tumors. This is important because tumors may have genetic variation that can inform why a treatment did or did not work and help look for new treatments. 2. Healthy tissue samples. This is important for comparison to the cancerous tissue. Allows researchers to look for what changes occurred to make the tissue cancerous. 3. Fluids: blood (for ctDNA), Lymph or spinal fluid? Samples may be taken before the organs are removed and can be taken without removing the organs.

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The chest plate and top of the skull are returned. The organs are examined visually and any abnormal findings such as changes in color or markings are recorded. The weight of some organs is measured and recorded. Some organs such as the gallbladder are opened to examine contents and visually check the internal surface for abnormalities. Organs may be palpated. Some larger organs such as the liver are sectioned.

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Samples and tissues will be treated and preserved as needed for the type of research. May be preserved or frozen. May be added to tissue repositories, sent to labs for cell culture or other studies. (Some organs returned after examination?.) The patient and family can decide (if they want to limit what types of studies are done and?) whether the tissue is made available to other labs.

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Why:
JHU performs rapid autopsies to advance cancer research in areas of cancer prevention, diagnosis and treatment. Completing the autopsy shortly after death is necessary to obtain samples of tissue that have the potential to grow. Completing a full autopsy allows the pathologist to examine how the cancer has progressed. This is important because current medical imaging and testing cannot reveal everything about how and where a cancer has grown and the risk of performing additional procedures that may reveal this information to the patient does not outweigh the benefit. The autopsy is completed by a medical doctor called a Pathologist. Will not change the quality of care or reduce cost of care, ownership of specimens, will not benefit or profit from the research

Time Frame:
Takes longer, completed in ~4-6 hours; Starts sooner, 6-12 hours after death (<6 ideal)

External Observations:
Includes observation and documentation of any marks on the body. Swelling, bruises, etc.

Incision Locations:
Sterile procedure (skin sterilized at incisions, sterile scalpel used) 1. Y-shaped: from shoulders to bottom of sternum to pubic bone (around naval) 2. U-shaped: from shoulders across mid sternum to pubic bone (around naval) 3. Ear-to-ear: over the crown of the head to access the brain. No incision needed for the eyes.

These incisions are required for a complete autopsy. The patient and family will discuss the procedure (with oncologists?) and decide whether they want a full or partial autopsy. If partial, the patient and family will decide what parts of the procedure will and will not be completed. Having a full autopsy does not prevent having an open casket memorial service.

Organs Removed:

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Cancer Development

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The process will typically begin with a discussion between the patient/family and the oncologists. At this time the reason for the research and participation process is explained. If the patient/family decides to participate in the legacy gift program they will sign a consent form to say they agree to participate in the study. There is no cost to the family for participation. Cost for report? Is this when the patient/family determine if full or partial autopsy and any modifications to tissue collection or dissemination/modifications to the standard autopsy process?

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Cancer Development

Traditional Procedure

Rapid Procedure

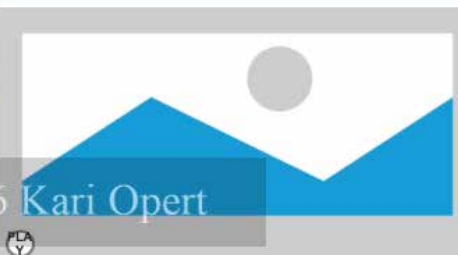
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JHU will organize the transportation arrangements with the funeral home (of the family's choice?)

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After the patient has passed, a family member or caretaker will notify JHU. If not completed already, the next of kin will sign a second consent form to say they agree to have the autopsy procedure preformed. The procedure will not take place without this consent. JHU will contact the funeral home to transport the patient for the procedure. It is called a rapid autopsy procedure because it is necessary to preform the procedure within 12 hours after the patient passes. Although sooner is better, we understand it is important that the family and loved ones take the time they need with the patient after she has passed.

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The autopsy procedure usually takes ~4-6 hours. After it is complete, JHU will contact the funeral home to transport the decedent to be prepared for the memorial service. Having a full autopsy does not prevent an open casket memorial service.

Donation Benefits

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Appendix C: Storyboards

Why

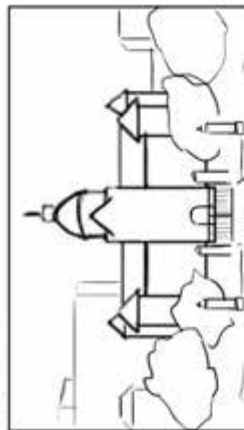
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Client: Jody Hooper M.D.

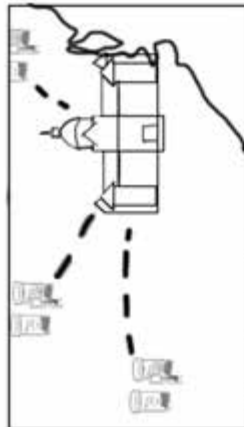
Date: February 3rd, 2014

Version: 1.0

KD post
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Audio: Jody Hooper, University



Audio: Jody Hooper, rapid autopsy



Audio: Jody Hooper, rapid autopsy

Video: Jody Hooper

Video: Jody Hooper, rapid autopsy

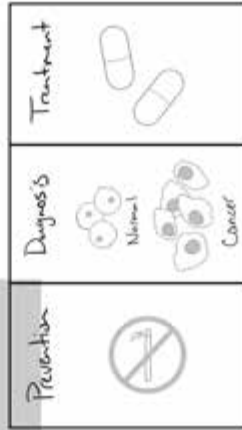
Video: Jody Hooper, rapid autopsy



Audio: Jody Hooper, rapid autopsy



Audio: Jody Hooper, rapid autopsy



Audio: Jody Hooper, rapid autopsy

Video: Jody Hooper, rapid autopsy

Video: Jody Hooper, rapid autopsy

Video: Jody Hooper, rapid autopsy

1/7

Project: Rapid Autopsy Patient Education: JHU Rapid Procedure - Why

Client: Jody Hooper M.D.

Date: February 3rd, 2016

Version: 10

KD post
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Audio: Performing the procedure shortly after death is needed to obtain...

Video: *X file*

Just on
Hungry and numbers on one by one



Audio: Samples of tissue

Video: *Smiley calls*



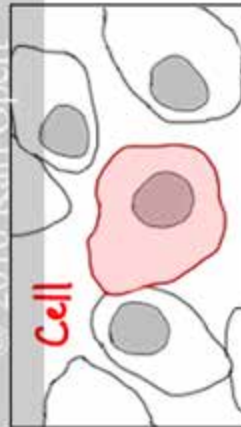
Audio: ...with living cells...

Video: *Smiley goes*
Smiley, Smiley



Audio: That looks like...

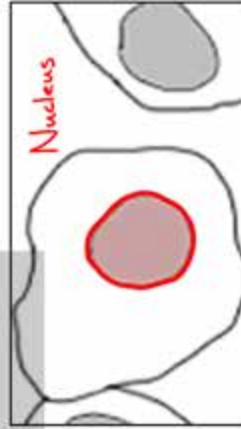
Video: *Zoom*



Audio: potential to grow

Video: *Zoom*

Highlight + heart on



Audio: or have passed...

Video: *Highlight + text x8*

Highlight + heart on

Project: Rapid Autopsy Patient Education: JHU Rapid Procedure - Why

Client: Jody Hooper M.D.

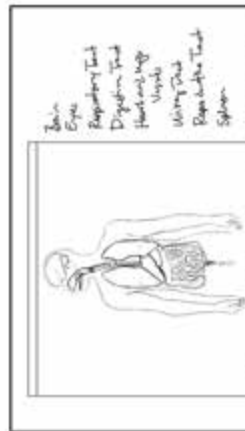
Date: February 3rd, 2016

Version: 10

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Audiot: ...DNA and RNA



Audiot: Performing a complete autopsy allows the pathologist to examine...



Audiot: ...how and where the cancer has spread

Video: Highlight + text off

Zoom: ...

DNA + RNA + text on



Audiot: This is important because current medical imaging

Video: Text + Arrows off

Highlight on

Highlight on

Video: X fade

Text on, we live at a time

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Audiot: cannot reveal everything about...

Video: Radiograph off

CT on

Highlight on

Video: Zoom

Text on, we live at a time

Zoom: ...

Text on, we live at a time

Text on, we live at a time

Text on, we live at a time

Text on, we live at a time

Text on, we live at a time

Text on, we live at a time

Text on, we live at a time

Text on, we live at a time

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Text on, we live at a time

Text on, we live at a time

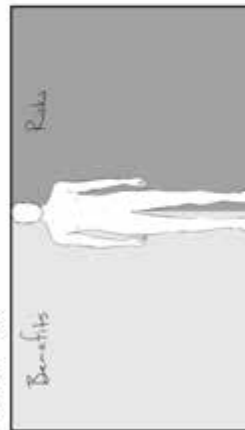
Project: Rapid Autopsy Patient Education: JHU Rapid Procedure - Why

Client: Jody Hooper M.D.

Date: February 3rd, 2014

Version: 10

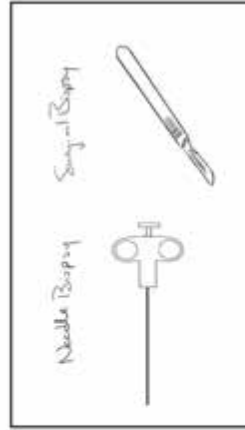
KO post
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Audior: *There may also be too much risk.*



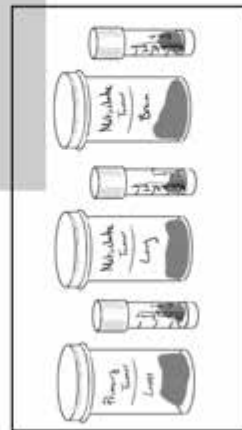
Audior: *As the patient to perform invasive.*



Audior: *procedures that might reveal this.*

Video: *X file background on*

Video: *Side Left*



Audior: *information during life.*

Video: *X file*



Audior: *The procedure is completed by a team lead by a medical doctor called a pathologist.*

Video: *X file background*
Life insurance on
Right insurance on
Pathologist on

Audior: *A complete*

Video: *X file*

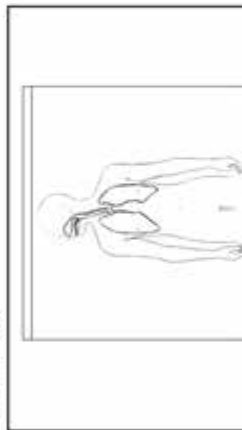
Project: Rapid Autopsy Patient Education: JHU Rapid Procedure - Why

Client: Jody Hooper M.D.

Date: February 3rd, 2014

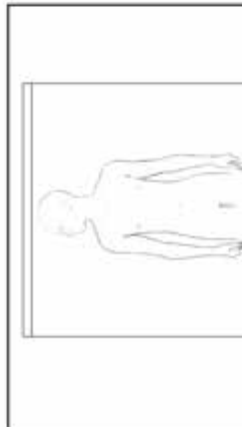
Version: 10

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Audiotape includes all of the organs...including the brain...and all these...institutions...

Video: each organ system is like one after the other



Audiotape: the organs will

Video: the organs will



Audiotape: Handwritten consent...

Video: X file



Audiotape: always be made to the procedure at

Video: Handwritten background all



Audiotape: the family request for example...

Video: Checklist: After
Handwritten on
light blue paper, from under box



Audiotape: the family can request...

Video: ✓ box

5/7

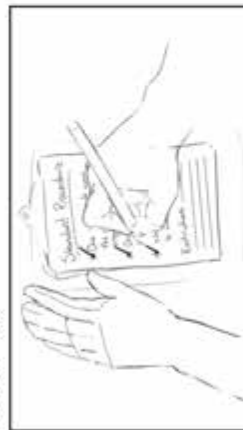
Project: Rapid Autopsy Patient Education: JHU Rapid Procedure - Why

Client: Jody Hooper M.D.

Date: February 3rd, 2016

Version: 10

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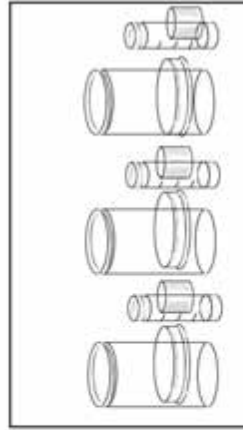
Audior: ...a short exam only

Video: ✓ next 2 boxes



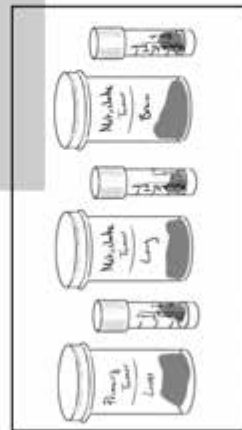
Audior: ...or restrictions to other areas of the body

Video: write restriction request



Audior: or may request that only...

Video: ✗ file



Audior: ...samples for research are removed

Video: Samples taken on body box on



Audior: However, this may limit

Video: ✗ body



Audior: what can be learned from the autopsy

Video: Sign + date

Project: Rapid Autopsy Patient Education: JHU Rapid Procedure - Why

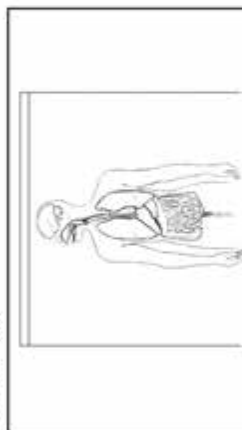
Client: Jody Hooper M.D.

Date: February 3rd, 2016

Version: 10

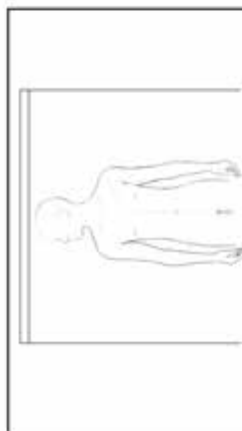
KO post

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Audio: Having a complete autopsy does not prevent or affect a

Video: ~~Slide~~ organs left in place at the time of autopsy



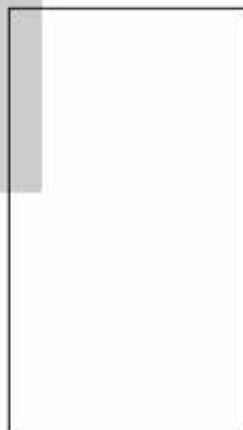
Audio: viewing or open casket service

Video: organs left in place at the time of autopsy



Audio: viewing or open casket service

Video: organs left in place at the time of autopsy



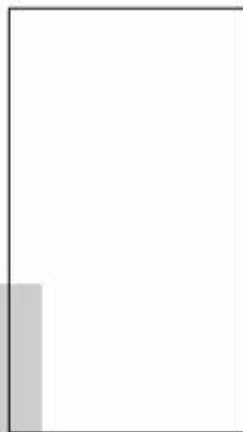
Audio: viewing or open casket service

Video: organs left in place at the time of autopsy



Audio: viewing or open casket service

Video: organs left in place at the time of autopsy



Audio: viewing or open casket service

Video: organs left in place at the time of autopsy

7/7

Time Frame

Project: Rapid Autopsy Patient Education: JHU Rapid Procedure - Time Frame
Client: Jody Hooper M.D.
Date: January 31st, 2016
Version: 1.0
 ~19.5 min
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K Opert



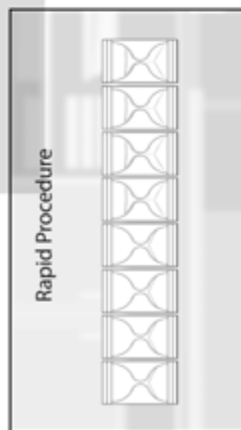
Audio: The procedure...

Video: Fade on background
 Fade text on



Audio: ...with voice...

Video: Fade click on



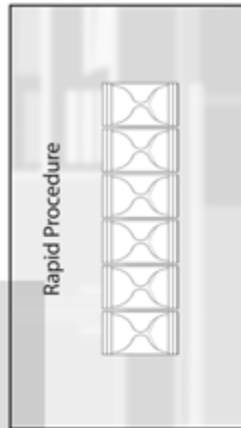
Audio: ...to 8 hours

Video: Fade back then



Audio: This is longer than a traditional autopsy
 but the procedure will also start sooner.

Video: Rapid click slide ←
 Fade traditional click on
 Fade back then
 "4.1 hours" on
 "5 hours" on

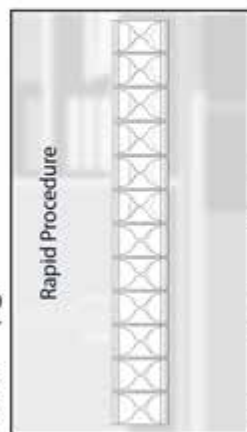


Audio: It is ideal to begin the procedure within 6 hours
 after death but it can be started...

Video: "4.1 hours" and "5 hours" fades off
 Traditional click fades off
 Rapid click back to center
 "Time up back to 0"
 Fade back to 0

Project: Rapid Autopsy Patient Education: JHU Rapid Procedure - Time Frame
Client: Jody Hooper M.D.
Date: January 31st, 2016
Version: 1.0

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Audios: up to 12 hours after death

Audios: After the procedure is

Audios: complete the patient is

Videos: How long the is

Videos: ~~X~~ *Camera for inside*

Videos: pulls some chains



Audios: ... returned to the forensic home

Audios:

Audios:

Videos: pick up phone

Videos:

Videos:

External Observations

Project: Rapid Autopsy Patient Education: JHU Rapid Procedure -- External Observations ~1054

Client: Jody Hooper M.D.

Date: January 8th 2016

Version: 1.0

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Audio: The procedure...

Video: Focus on background



Audio: ...begins with...

Video: Focus on screen



Audio: ...an external team

Video: Focus on hand



Audio: This includes documentation of basic characteristics such as...

Video: Point out features



Audio: ...their body...

Video: ...off



Audio: ...eye color...

Video: ...off

1/2

Project: Rapid Autopsy Patient Education: JHU Rapid Procedure -- External Observations *by J. Hooper*

Client: Jody Hooper M.D.

Date: *January 28th 2016*

Version: 1.0

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Audio: ... and the findings.

Video: Point to areas of findings.



Audio: ... medical information and any notes of medical procedure.
... and the findings.

Video: Write Findings.



Audio:

Video:



Audio:

Video:



Audio:

Video:



Audio:

Video:

2 / 2

Incision Locations

Project: Rapid Autopsy Patient Education: JHU Rapid Procedure - Incision Locations

Client: Jody Hooper M.D.

Date: January 24, 2016

Version: 1.0

KO post
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~ 42 yds



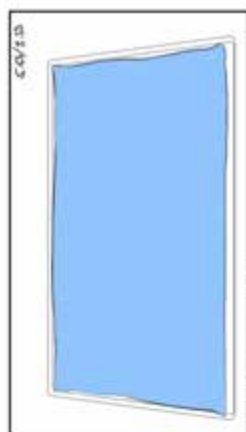
Audiot: Sterile procedure.

Video: Face on



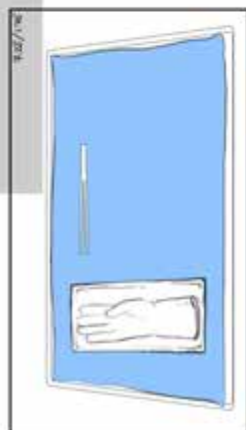
Audiot: ...is used for the version and sample collection.

Video: ~~Face~~ *Whole head*



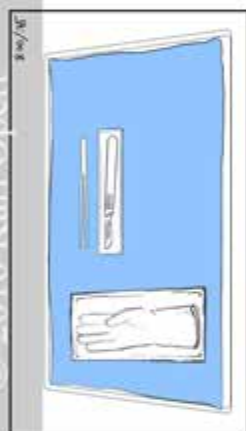
Audiot: This means that there is

Video: ~~Face~~



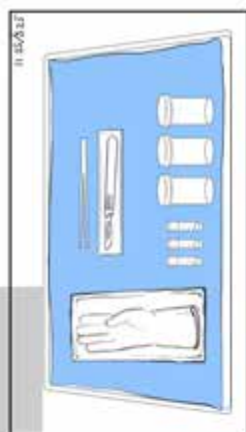
Audiot: ...gloves and instruments, such as the...

Video: gloves on
fringe on



Audiot: ...scalpel and...

Video: Scalpel on



Audiot: ...sample containers are sterile and that the other is checked with...

Video: Containers on

1/4

Project: Rapid Autopsy Patient Education: JHU Rapid Procedure - Incision Locations

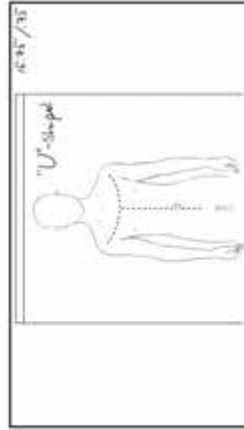
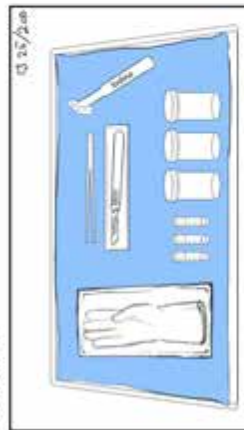
Client: Jody Hooper M.D.

Date: January 24, 2016

Version: 1.0

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~42 sec



Audios: ...after at the incision.

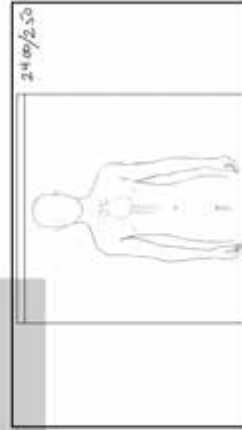
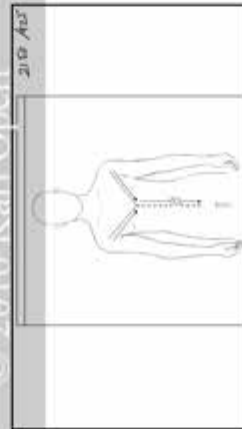
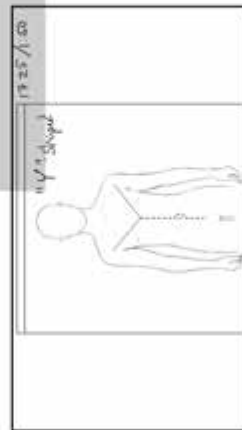
Audios: A full autopsy incision is...

Audios: ..."U"-shaped incision.

Videos: ...video on

Videos: X file
for video on

Videos: X file
for video on



Audios: ..."U"-shaped incision from the...

Audios: ...incision to the sternum to the pubic bone
and around the neck along...

Audios: ...near to the organs and major vessels and so...

Videos: X file
for video on

Videos: Autopsy incision to rectus abdominis

Videos: Organs incision. Incision on

2/4

Project: Rapid Autopsy Patient Education: JHU Rapid Procedure - Incision Locations

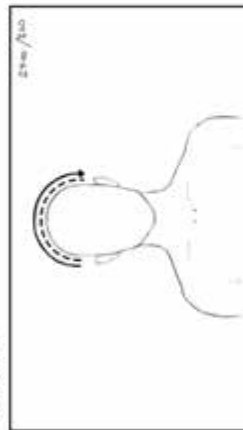
Client: Jody Hooper M.D.

Date: January 24, 2016

Version: 1.0

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~472 sec

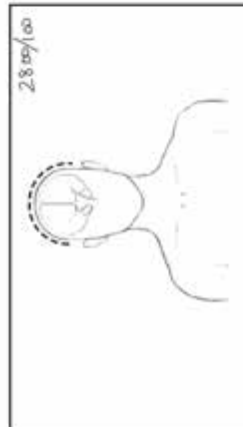


27:00/1:00

Audios: ...incision around the neck, at the head, to access the...

Video: Zoom in

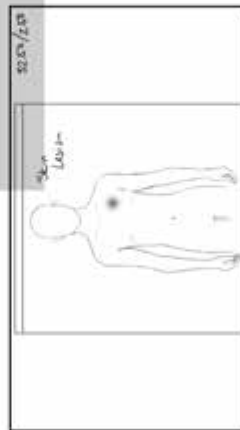
Arrows indicate screen



28:00/1:00

Audios: ...skull and brain...

Video: Brain on / Arrows on

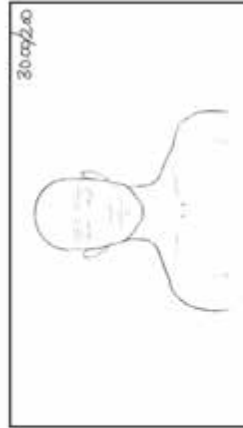


32:57/2:37

Audios: If bone is present in other locations

Video: Zoom in

Arrows / up/down on

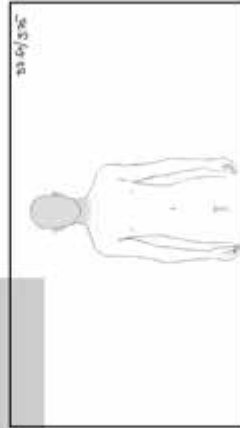


30:00/2:00

Audios: There is no incision to access the eyes

Video: Incision + brain bone off

up/down on



33:07/3:07

Audios: No incision which would be made during a viewing back on the head

Video:

3/4

Project: Rapid Autopsy Patient Education: JHU Rapid Procedure - Incision Locations

Client: Jody Hooper M.D.

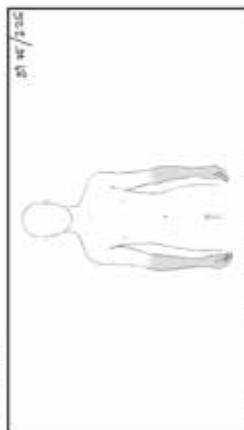
Date: January 24, 2016

Version: 1.0

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~ 472 sec



Audiotape: ... arms and hands ... will be sampled ...

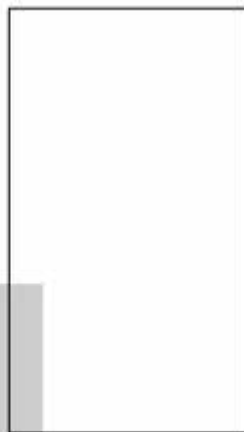
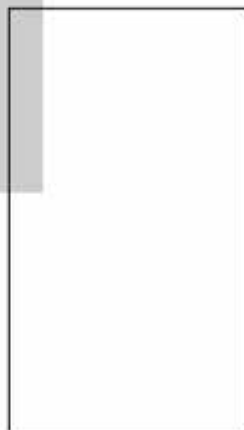
Audiotape: ... without special permission from the family

Audiotape:

Video:

Video: ☒ file

Video:



Audiotape:

Audiotape:

Audiotape:

Video:

Video:

Video:

11 / 14

Organs Donated

Project: Rapid Autopsy Patient Education: JHU Rapid Procedure - Organs Donated

Client: Jody Hooper M.D.

Date: January 28, 2016

Version: 1.0

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~44 sec



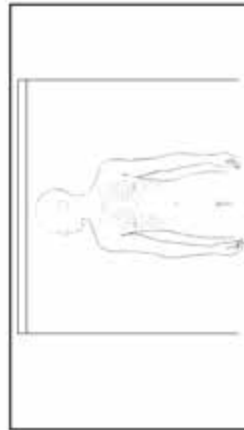
Audios: *He...*

Videos: *Feet on*



Audios: *chest plate*

Videos: *Feet on*



Audios: *...a stroke to cause the...*

Videos: *chest plate, feet on*



Audios: *heart and lung vessels, the...*

Videos: *heart on*



Audios: *respiratory tract including the trachea and lungs, the...*

Videos: *entire respiratory tract*



Audios: *digestive tract including the tongue, esophagus, stomach, intestines, liver, gallbladder and pancreas, the...*

Videos: *entire digestive tract*

Project: Rapid Autopsy Patient Education: JHU Rapid Procedure - Organs Donated

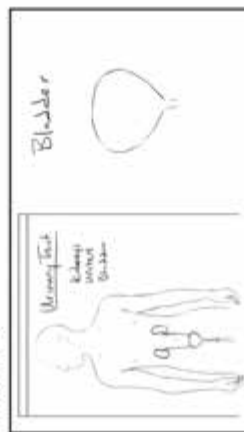
Client: Jody Hooper M.D.

Date: January 28th 2016

Version: 1.0

KD post
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~44:00



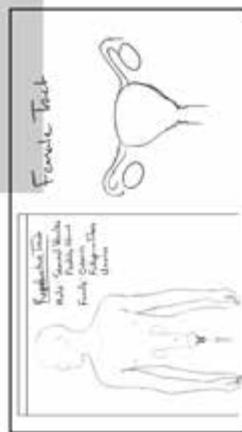
Auditor: ...urinary tract ...kidneys, ureters, and bladder...

Video: ...trunk ...organs ...on ...red ...with ...on ...can...



Auditor: ...adrenal glands ...adrenal glands ...the...

Video: ...organs ...on ...can ...with ...on ...can...



Auditor: ...reproductive tract...

Video: ...organs ...on ...with ...on ...can...



Auditor: ...digestive tract...

Video: ...all organs ...from ...the ...gut...



Auditor: ...circulatory system ...all ...on ...the ...can...

Video: ...organs ...from ...the ...gut...

Project: Rapid Autopsy Patient Education: JHU Rapid Procedure - Organs Donated

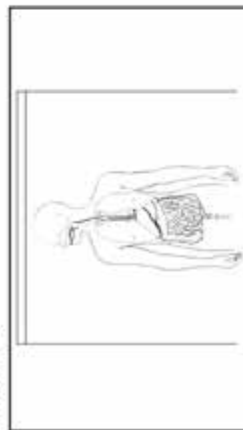
Client: Jody Hooper M.D.

Date: January 28th 2016

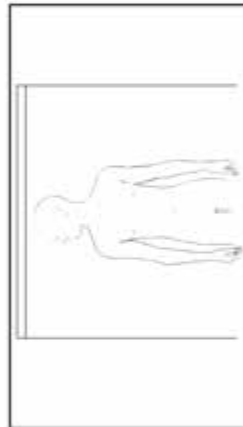
Version: 1.0

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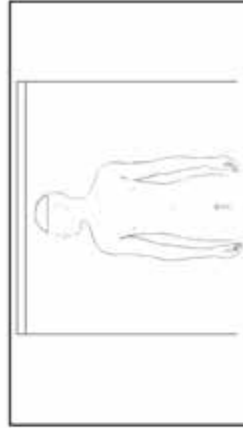
~44:00



Audios: organs may be removed in separate sections depending on the case.



Audios: organs may not be removed if that is the family's preference.



Audios: the top of the skull.

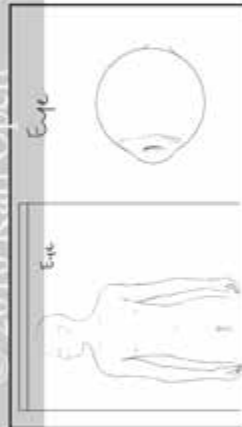
Video: all organs. Tissue are all organs. Tissue are all organs. Tissue are all organs.

Video: all organs on

all organs. Tissue are all organs. Tissue are all organs.



Audios: - to get inside to reach the brain.



Audios: No incision is needed to reach the eyes.



Audios: At the end of the procedure, the chest plate and top of the skull are returned.

Video: skull will after

Video: brain is after eye on

Video: Zeeva's out Chest Plate back on

Samples Donated

Project: Rapid Autopsy Patient Education: JHU Rapid Procedure - Samples Donated

Client: Jody Hooper M.D.

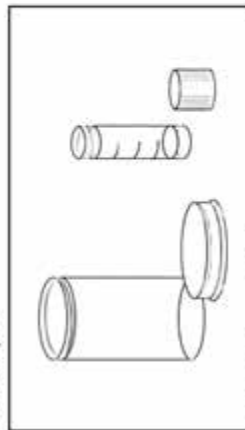
Date: January 27th 2016

Version: 1.0

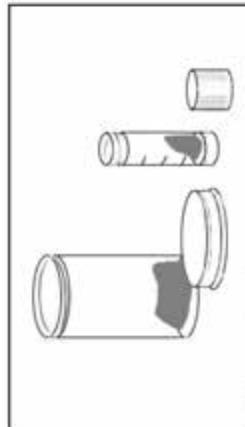
KO post

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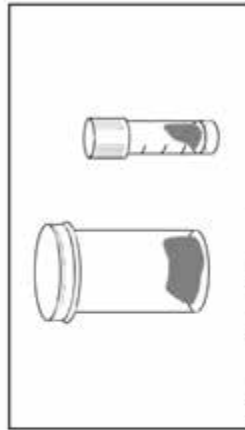
~32:50



Audior: Samples are collected here.



Audior: ...some tissue from...

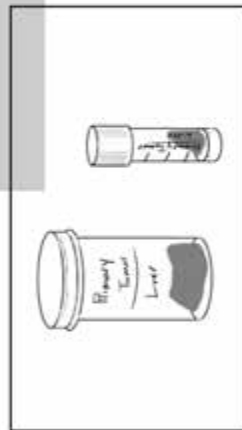


Audior: ...different locations at...

Video: Containers both are
lids off

Video: Forceps place specimens in

Video: Lids on



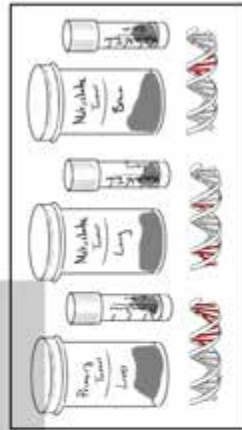
Audior: ...primary and...

Video: Labels on



Audior: ...necrotic tissue

Video: Primary slide left
Necrotic slide on



Audior: This is important because tissues may have genetic
alterations...

Video: DNA on
Highlight each tissue from L+R. Different in here and

Project: Rapid Autopsy Patient Education: JHU Rapid Procedure - Samples Donated

Client: Jody Hooper M.D.

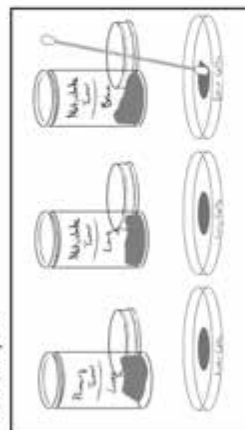
Date: January 27th 2016

Version: 1.0

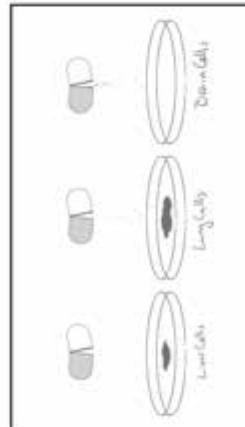
KO post

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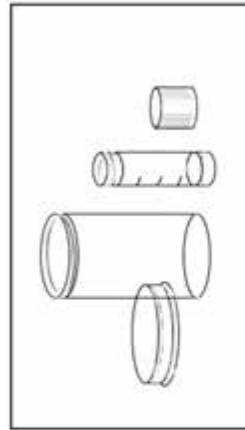
~\$2.50



Audiot: ...that can often, when a treatment did not work, and help the...

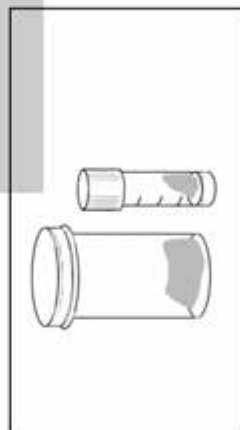


Audiot: ...specimens for new treatments.



Audiot: Samples...

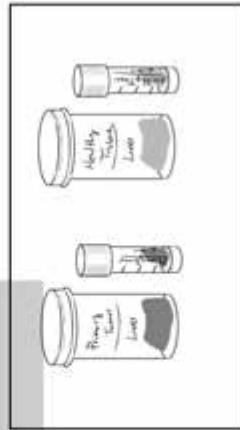
Video: DNA after
Extraction / Data on
Samples on the bench



Audiot: ...one also collected from...



Audiot: ...tissue



Audiot: ...this is important for comparison to the
...Genomic Profile...

Video: Tissue samples in
tubes on

Video: Labels on

Video: Health samples shrink/shrink Right
Tissue Samples on

Project: Rapid Autopsy Patient Education: JHU Rapid Procedure - Samples Donated

Client: Jody Hooper M.D.

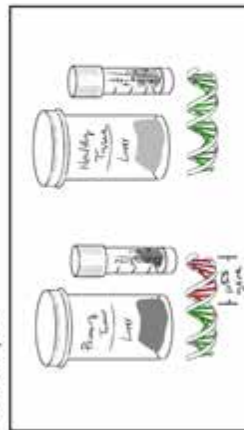
Date: January 27th 2016

Version: 1.0

KO post

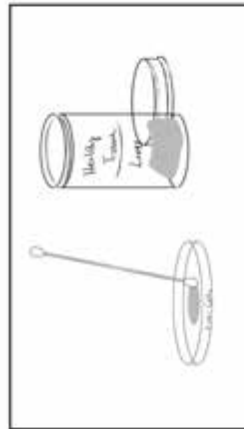
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~\$2.50



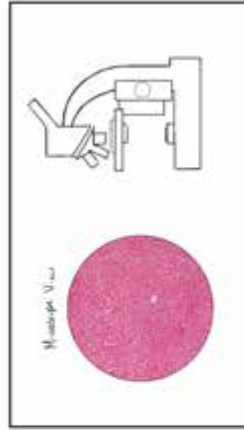
Audio: ...to find the change that makes cancer worse

Video: DNA is brought back to the lab. Tissue from the



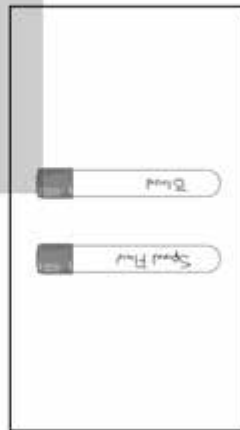
Audio: Some researchers also need tissue for

Video: Genes/Tissue Samples are taken from the



Audio: ...other type of non-cancer research.

Video: Samples continue off microscope and data stored online to microscope



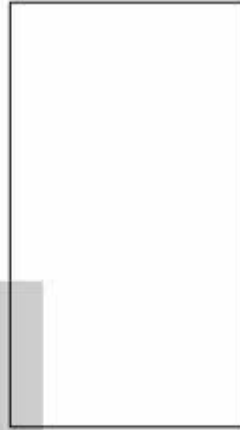
Audio: Finally, fluid such as spinal fluid and blood

Video: ~~File~~ Labels on



Audio: ...not collected

Video: Fill



Audio:

Video:

Organs Examined

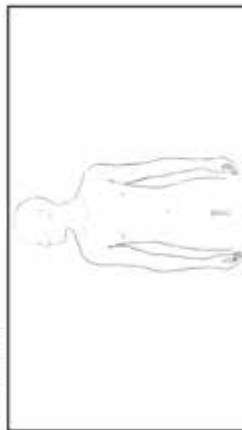
Project: Rapid Autopsy Patient Education: JHU Rapid Procedure - Organs Examined

Client: Jody Hooper M.D.

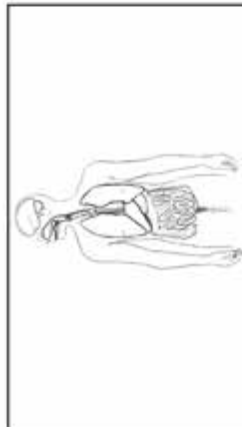
Date: February 1st, 2016

Version: 1.0

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Auditor: At organs in



Auditor: removed, usually



Auditor: not any, almost being

Video: Body falls in

Video: Organs fall in

Video: Body + organs fall off
Last step of surgery
Test on



Auditor: looks on changes in color of pathology set
recorded



Auditor: The weight of the organs is measured and
recorded



Auditor: Organs look on the gallbladder

Video: Test should take
Liver, gall bladder, stomach
digestion
blood testing

Video: Test all / Liver drains
Suck in
Liver inside
that from the top
what weight

Video: ~~X~~ falls
Test on
check how on

1/3

Project: Rapid Autopsy Patient Education: JHU Rapid Procedure - Organs Examined

Client: Jody Hooper M.D.

Date: February 1st 2016

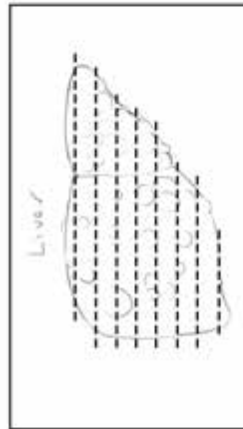
Version: 1.0

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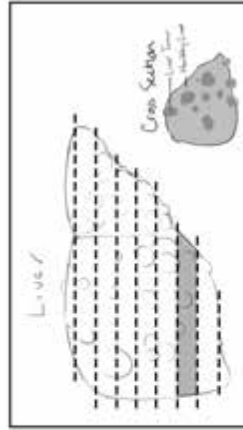
Audiotape: Organ examination, and check the internal surface for abnormalities.

Video: ~~Examination~~
The video will be a combination of a
combination of
both the
both the



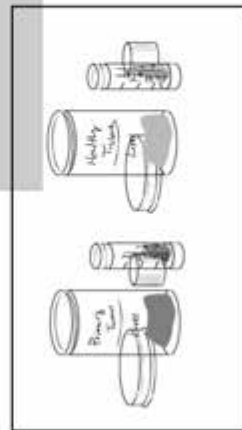
Audiotape: Solid organ, such as the liver, are sectioned.

Video: ~~Examination~~
The video will be a
combination of a
combination of



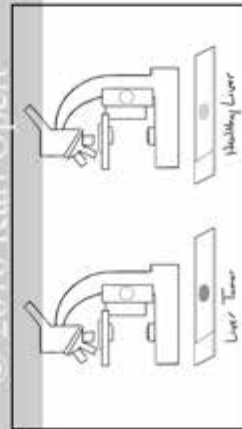
Audiotape: For examination.

Video: ~~Examination~~
The video will be a
combination of a
combination of



Audiotape: Samples of organs are taken to be

Video: ~~Examination~~
The video will be a
combination of a
combination of



Audiotape: microscope slides.

Video: ~~Examination~~
The video will be a
combination of a
combination of



Audiotape: For examination.

Video: Microscope slides, none, upper left
The video will be a
combination of a
combination of

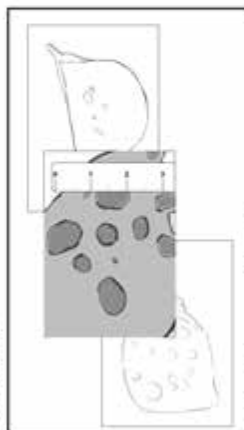
Project: Rapid Autopsy Patient Education: JHU Rapid Procedure - Organs Examined

Client: Jody Hooper M.D.

Date: February 1st 2016

Version: 1.0

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Audio: Embryo are photographed.

Video: Photos are on site in front.



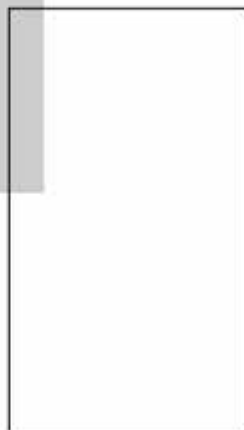
Audio:

Video:



Audio:

Video:



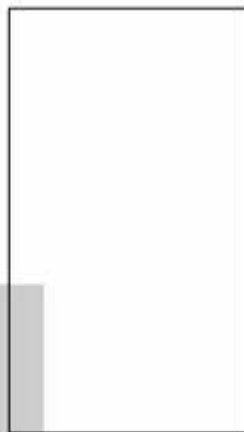
Audio:

Video:



Audio:

Video:



Audio:

Video:

3/3

Tissue Destination

Project: Rapid Autopsy Patient Education: JHU Rapid Procedure - Tissue Destination

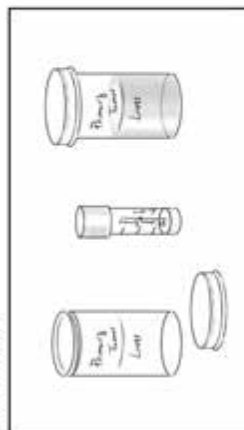
Client: Jody Hooper M.D.

Date: January 29th, 2016

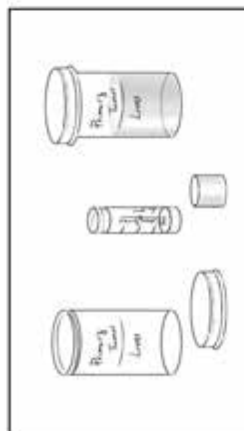
Version: 1.0

KO post

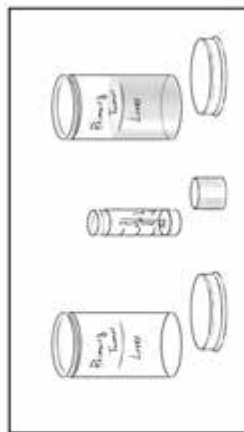
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Audiot: Tissue



Audiot: Tissue, lipid



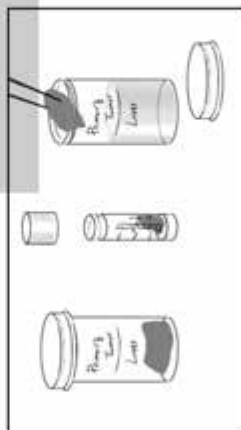
Audiot: Tissue, lipid

Video: Tissue, lipid

Video: Tissue, lipid

Video: Tissue, lipid

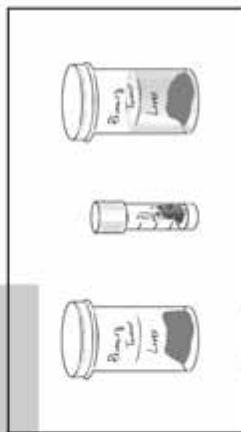
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Audiot: samples are taken at most rapid research autopsy for use in...



Audiot: different types of research



Audiot: If the family wants...

Video: 1st Culture: Sample placed, lid on
2nd Culture: Sample placed, lid on
3rd Culture: Sample placed, lid on
Zoon - out

Video: Study types for one of a few

Video: X-Risk

1/4

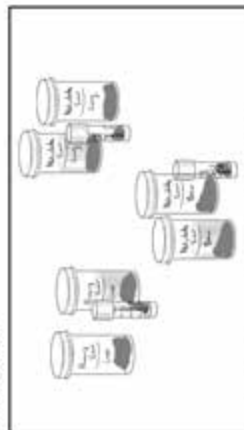
Project: Rapid Autopsy Patient Education: JHU Rapid Procedure - Tissue Destination

Client: Jody Hooper M.D.

Date: January 29th, 2016

Version: 1.0

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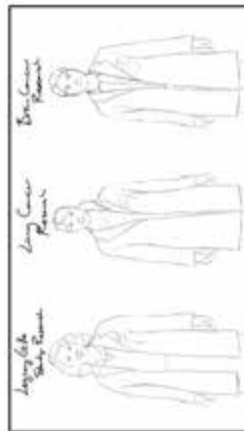
Audio: Samples can be taken for different...

Video: Live samples combine patient/shrink
Other samples like an



Audio: With permission, samples can also be sent to
researchers at different institutions

Video: ~~Files to send (like in)~~
Other institutions can
Samples distributed



Audio: researchers, including those seeking

Video: ~~File with multiple researcher on~~
Right Researcher File
Left Researcher File on



Audio: The patient and family can...

Video: ~~File~~



Audio: normal as well as cancer tissue

Video: Multiple + Right researcher file off
~~File with multiple researcher on~~
Right Researcher File
Left Researcher File on



Audio: decide at the time of diagnosis

Video: ~~File on~~
Family tree

2/4

Project: Rapid Autopsy Patient Education: JHU Rapid Procedure - Tissue Destination

Client: Jody Hooper M.D.

Date: January 29th, 2016

Version: 1.0

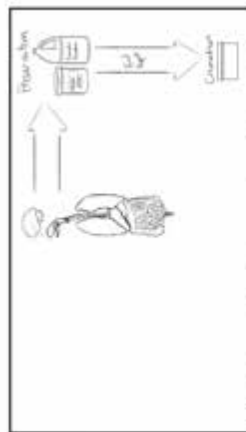
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Audios: ...consent what type of studies may be done...



Audios: ...and where the tissue may be sent

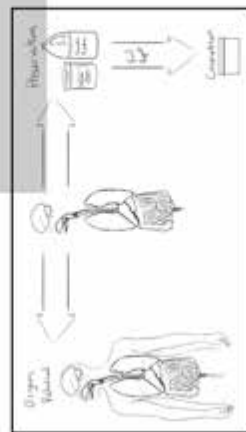


Audios: Organ will usually be preserved in formalin and kept until the autopsy report is finished, after which they will be sent to...

Video: ...left background / Fade out 60%
...in Consent
...have

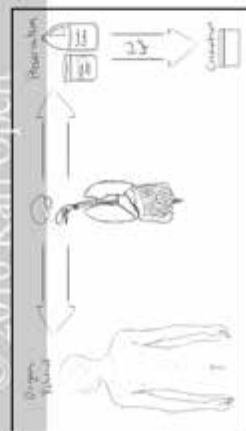
Video: ...center lines

Video: ...fade in organ as
...center line and
...center line and
...center line and
...center line and
...center line and



Audios: The family are request that organs be returned

Video: ...center white out 10%
...fade in
...fade in



Audios: ...at the time of the autopsy

Video: ...organ fade 20% when time fill out



Audios: when the autopsy procedure is...

Video: ...fade
...fade up to fill rest done

Project: Rapid Autopsy Patient Education: JHU Rapid Procedure - Tissue Destination

Client: Jody Hooper M.D.

Date: January 29th, 2016

Version: 1.0

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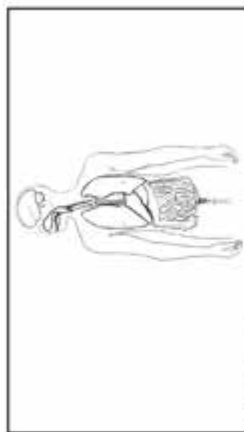
Audior: Complete the thyroid gland is outlined.

Video: Full neck down



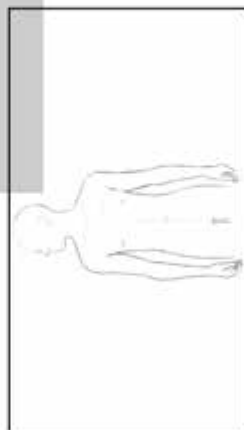
Audior: An enlarged thyroid gland will appear the body for the internal organ.

Video: Pin up



Audior: A complete autopsy including the eye.

Video: Open back on
Body on
Eye on



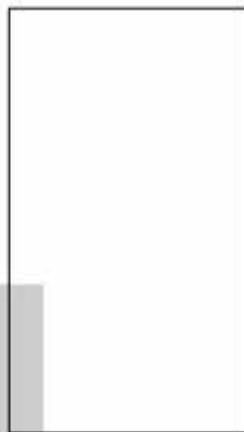
Audior: will take about 15 minutes at a normal rate.

Video: Open back, left / Stereoscopic fill in
Light source must be on



Audior:

Video:



Audior:

Video:

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Vita

Kari Opert was born in Baltimore, Maryland on February 21, 1989. From an early age, she had an inclination for the arts and sciences. She pursued these interests by attending Patapsco High School and Center for the Arts and continued to foster her artistic talents by attending additional programs including The Marie Walsh Sharpe Art Foundation Summer Seminar in Colorado Springs and the Maryland Institute College of Art pre-college program. Kari went on to complete her undergraduate degree at the Maryland Institute.

While in her sophomore year, Kari began seeking a way to use her developing artistic and visual communication skills and learned of the field of medical illustration. During the summer of 2009, she completed an internship with a medical illustrator in the publishing department of Sinai Hospital's Rubin Institute for Advanced Orthopedics. Realizing this was the perfect field for her to merge her love of art, visual communication, and science, Kari began to complete her scientific coursework at Towson University. After summer course spent painting in Italy and completing her undergraduate degree, she continued her scientific coursework and started working at the Johns Hopkins Center for Immunization Research.

In 2014, Kari began her studies with the Department of Art as Applied to Medicine at Johns Hopkins University and will receive her Master of Arts degree in May of 2016. She looks forward to continuing her work with medical and scientific professionals and using visual media to communicate and share scientific knowledge in an engaging and efficient manner.